HealthCare Consumers

Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project

Final Report

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Supported by

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Introduction

The Health Care Consumers' Association

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services
- research into consumer experience of human services.

HCCA is committed to **consumer-centred care**[1] as a foundation principle in all its work and to promoting consumer-centred care across the health system, within government and across the ACT community. Consumer-centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.[2]

HCCA was asked by the Health Directorate and the Minister for Health to explore the experiences of families whose children received interstate health care, as the Minister's attention had been drawn to some of the difficulties they faced. The Minister wanted these issues addressed as soon as possible. This is the final report of the Project. Both the Minister and the Directorate have been provided with an Interim Report on the research at the end of January 2020 and some possible recommendations for action were also provided at the Minister's request in early March this year.

HCCA commissioned Dr Fiona Tito Wheatland from Enduring Solutions to complete this work. The work was carried out by Dr Tito Wheatland and Anna Tito of Enduring Solutions and until November 2019, Dr Kristal Coe of HCCA.

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[1] Different people use different words to describe consumer-centred care, including person centred care, patient and family centred care, client centred care, and patient centred care.

[2] HCCA Position Statement on Consumer-centred Care http://www.hcca.org.au/about-hcca/position-statements.html

Acknowledgements

HCCA would like to thank the families and carers, health professionals and advocacy groups who have spoken to us. We hope that this Final Report provides an insight into the experiences described to us and a foundation to improve the process and outcomes for people whose kids require interstate shared care. We are deeply grateful for all your help and honesty. We were very moved by your stories and deeply committed to addressing some of the failings in the system which have made your difficult experiences even harder. As a community, we need to do better.

Given the relatively small number of children in interstate care, the small number of stakeholder organisations and the relatively small numbers of paediatric doctors, nurses and social workers who participated in the research, we have chosen to maintain their anonymity throughout this document as much as possible through attributing the quotes simply to “Consumer Participant”, “Stakeholder Participant” or “Health Services Participant”. People may recognise themselves and their words, but we wanted to ensure that people felt safe being honest. Where children are still receiving care, parents may fear that expressing criticisms of the system will be “held against them” and make further services more uncomfortable. The decision to anonymise individual participants was made to reduce the likelihood that individuals would be recognised by others and alleviate this fear.

Executive Summary

In almost every interview with parents whose children required or had required interstate care or shared care, they stated that their reason for participating was to ensure that other parents and children or young people did not have face the same difficulties they had experienced.

> *"Most of us just want to make the system better so the next kid and the next family don't have to go through it..."- Consumer Participant*

The hardest point in most of the interviews came when the question was asked by the interviewer "So what actually worked well for you so we can ensure this continues?" Almost without exception, what followed was an uncomfortable silence followed by a simple phrase "nothing really", with various degrees of animation. There were a few interviewees who referred to a particular person who seemed to really care and listened to them, or who had gone out of their way to make sure they knew what was happening and had been kind. However, overall their experiences had been bleak and had undermined their faith that compassionate, kind, caring and capable health services that they needed as a family would be readily available.

While there were a few marked examples of rudeness and actual cruelty, most people described a system which was simply careless of their family's needs, ignorant of likely issues and dismissive of their concerns. These were experienced at both ends of the shared care arrangements. People often spent many hours organising appointments, travelling long distances getting to appointments, waiting for many hours to see someone who was hurried and harried and a poor communicator, then travelling back again with a sick child. Where children were in the acute or early phases of their illness, this could happen several times a month and sometimes more than once a week.

The interviewees were almost always articulate advocates and highly capable record keepers and carers. However, their observations and suggestions about their child's condition or needs were often ignored by health professionals. Parents often described situations where they were treated with disrespect or condescension. Several referred to clinicians (both nursing and medical staff) who would make comments about parents "choosing to have care interstate" as if they were disloyal, when in fact, often that was the only possible choice.

These childhood diseases and conditions affect families across all socio-economic and educational groups. They occur for families or individuals who may be culturally or personally less assertive, less organised, whose comprehension or literacy may make understanding what is said more difficult or they may be temporarily overwhelmed. If the experiences of those who are more articulate, educated and organised are bad, then the experiences of those who aren't is likely to be even less positive. There are community, Government and professional responsibilities to address these shortcomings for people whose children require care interstate and in Canberra.

Addressing these issues is also required by the National Safety and Quality Health Service (NSQHS) Standards, which must be met for health services and hospitals to be accredited. Many of the failures identified in current shared care arrangements produce unsafe care situations for vulnerable children and young people. While direct risks to patients should be our primary concern, failure by health services and hospitals to systematically attend to these ethical, legal and regulatory requirements exposes health services and health professional themselves to financial and reputational risks.

The recommendations set out below seek to provide a path forward, the text of the report provides further details in relation to these recommendations. The recommendations are based on common suggestions made by families, other stakeholders and health staff who participated in the project. They cover four main areas:

- Care coordination
- Information
- Improving hospital and health care experiences for children and their families
- Supporting the family and the child beyond immediate care

Inconsiderate attitudes and lack of kindness and care that was apparent in the behaviour of some health professionals to both the children and parents in these situations caused unnecessary additional trauma to them all. Changing this must come from the hearts of everybody involved with families whose children require interstate and shared care. Kindness and competence need to be spread thickly everywhere – across health services, education, community services and all people who touch their lives - to make these difficult journeys for children and families easier.

Recommendations for Action

A. Care Coordination

1. Establish an ACT Paediatric Nurse Liaison Service.
2. Introduce Patient and Family Navigators.
3. Establish processes to ensure continuity of care across hospital services.
4. Improve access to integrated multidisciplinary team rehabilitation and disability related services.

B. Information

5. Develop and introduce an information pack and diary for parents including an online resource.
6. Provide access to diagnostic imaging for interstate specialists.

C. Improving hospital and health care experiences for children and their families

7. Improve acute incident processes.
8. Upskill local paediatric staff.
9. Establish paediatric outpatient nursing role.

10. Implement holistic approaches to care.
11. Rethink the role of GPs in shared care arrangements.
12. Train paediatric and ED staff on the importance of family centred care.
13. Review the model of care in paediatric palliative care and the role of the paediatric palliative care nurse.

D. Supporting the family and the child beyond immediate care

14. Improve current ACT Interstate Patient Travel Assistance Scheme.
15. Explore options to make more lower-cost accommodation near shared care hospitals available or to increase the IPTAS subsidy to a level reflective of the real costs.
16. Enhance the range of support services for families.
17. Improve support for Schooling.

Context of the Project

The Minister for Health, Rachel Stephen-Smith MLA, and her predecessor Meegan Fitzharris MLA, were concerned about the issues raised by families whose children receive their care through interstate shared care arrangements. These, often complex, arrangements arise where the ACT Health system is unable to provide some or all of the care for their children, and the families need to travel to Sydney or other interstate destinations for care. This can be an issue for adult patients as well, but this broader context is beyond the scope of this research.

Our understanding is that one of the Minister's priorities for 2020 is to improve clinical services in Canberra for children with chronic conditions and children requiring specialist interstate care. This Research Project, funded by the ACT Health Directorate, provides insights into the last of these, but overlaps well with children who have chronic conditions, as many of these children's medical needs cannot be catered for in the ACT.

Why Interstate Care is Needed for Children in Canberra

Canberra Hospital is the largest regional teaching hospital in South East NSW and the Australian Capital Territory[3]. However, it still remains a relatively small hospital, in terms of patient throughput compared to hospitals in Sydney and Melbourne. This means that in some areas, and for some conditions, the number of people in the population needing particular services can be too small to support a specific subspecialty.

Health care services are often classified as primary, secondary, tertiary and quaternary services, with the degree of specialisation increasing from general "every day" care to very specialised services over that range. Secondary care is usually specialist care provided in a specialist doctor's room or through a specialist public clinic, often located in a public hospital. Tertiary and quaternary care implies a higher level of subspecialisation or services which provide higher levels of care in more complex cases.

In areas such as emergency medicine[4] and neonatal intensive care[5], Canberra Hospital is considered a tertiary level care provider. However, in others, like paediatric care, only secondary level services are available, and children will be referred to more specialised services interstate, usually in Sydney and sometimes in Melbourne.

In some paediatric situations, even secondary care may not be available in Canberra or may be very limited, and in these cases, the urgency of need for care may mean that the child and their family are required to access the majority of their care in Sydney or

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[3] https://health.act.gov.au/hospitals-and-health-centres/canberra-hospital

[4] http://health.act.gov.au/careers/medical-officer-training-and-recruitment/canberra-hospital/emergency-medicine

[5] https://nicucam.com.au/about

elsewhere interstate. The relatively small size of our population means that it is not possible now or in the foreseeable future to have permanent paediatric speciality or sub-specialty medical services available for all conditions.

There are many children impacted by this. For example, specialist services are not readily available for children with juvenile idiopathic arthritis, serious epilepsy, eating disorders, leukaemia, brain tumours, serious heart disease, certain injuries, cerebral palsy, genetic conditions, and muscular dystrophy to name a few. For some conditions, there are specialist doctors and teams, who visit from interstate and provide public clinics, such as a paediatric neuromuscular clinic and a neurologist. In other cases, there may be only a few Canberra specialists who work in the area. Often the waiting times for these clinics or individual specialists can be significant. This is a major concern for parents and children awaiting diagnosis or decisions on treatment. Not only does this cause anxiety for parents and children, but diagnostic delays can impact negatively on the child’s prognosis. As noted by one stakeholder participant:

> *“Prompt access to high quality health care is needed to manage muscular dystrophy and related neuromuscular conditions. Degeneration can occur quite quickly if appropriate care is not provided.” – Stakeholder Participant*

Another stakeholder participant noted that the failure to promptly diagnose some forms of Juvenile Idiopathic arthritis can lead to blindness. Where the child needs access to diagnostic and prompt advice post -diagnosis, parents are able to get into specialist care faster in either Sydney or Melbourne.

Parent and Carer Experiences at the Beginning of Interstate Shared Care

For Canberra parents whose children are diagnosed with serious, long term or life-threatening conditions, there is often a vacuum of information at the beginning of their journey. This can be about the child’s condition and what treatments and care they will require, but also about the various systems they will encounter as they care for their child. People are often not told what assistance is available locally, what can be provided when they are receiving care interstate and how to manage the costs and stresses which arise along the way.

Children with serious acute or chronic conditions who access interstate specialist services almost always need some of their care provided in Canberra. Firstly, they require primary care through their general practitioner. Good primary care can lessen the need for hospital care, so long as the general practitioner is seen as part of the care team and is provided with necessary advice from the interstate clinic or specialist about working with the family and the child in managing their condition. Secondly, the child can require ongoing multi-disciplinary care and rehabilitation related services, following an admission or post diagnosis, which need to be provided in Canberra.

Unfortunately, the necessary linkages which are necessary to enable good care to be provided across these different places of care either do not exist or are very dependent upon the good work of an individual who works around the barriers that exist to good quality, continuous care.

In other situations, where limited services or specialist are available in Canberra, poor experiences can mean parents are not happy with the quality of care their child is receiving in Canberra. Parents often also access interstate care when Canberra specialists or services have difficulty diagnosing what is happening for a child or when waiting times to even see a specialist are excessive.

Background to the Research

The ACT Minister for Health asked HCCA to undertake research on the experiences of children who require shared care and their families. To understand the broader context of these experiences, the researchers also needed to speak to those who provided the Canberra part of the shared care and look at what already existed to help families negotiating the complex task of helping their child through the process.

Stages 1 and 2 of the Research

The ACT Health Directorate contracted for the conduct of this research, through a variation of contract with HCCA in late September 2019. HCCA sought advice on the need for ethics committee approval for the research, but was advised by the Directorate that it was not human or medical research but a rather a quality improvement activity, so no ethics committee approval was needed. To ensure that the spirit of informed consent to participation in research was enacted, HCCA developed a Participant Information Sheet and an Interview Outline to provide to participants

The project was set out in 4 stages. Stages 1 and 2 included the Interim Report and all the following:

- environmental scanning;
- testing of the informed consent documentation for consumer interviewers and relevant information for health service staff;
- testing of the questions and interview process;
- development of an identification methodology for consumers;
- interviews with key staff from Canberra Health Service and other stakeholders; and
- preliminary thematic analysis.

Stage 3 was the interviews with consumers and stakeholders and completion of the thematic analysis and Stage 4 was the preparation of the Final Report.

The original proposal was that the Directorate would provide the contact information for people to be interviewed at Stage 3. The criteria for inclusion for Stage 3 were 15 consumers or families, where:

(a) The child has or has had a shared health care arrangement between Canberra Health Service and an interstate hospital or health service; or

(b) The child is currently or has previously received all their health care interstate; and

(c) The child or young person, resident in the ACT (who was aged 0-17 years at the time of receiving care) who has received specialist interstate care in the last 36 months and their families/carers.

HCCA began the parent/carer interviews with those people who had directly contacted the Directorate, the Minister or HCCA about their experiences, as agreed with the Directorate. These people were contacted, provided with the two documents for participants and interviewed. Several interviews were also conducted with key health staff. These first round of interviews tested the methodology, allowed us to refine the information sheets for participants and the themes raised were recorded in the Interim Report. We have included their results in the Final Report, with those of the Stage 3 participants.

Secondary Proposal for Recruitment for Stage 3 Interviews

Beyond this small group of self-nominating families, the initial proposed recruitment methodology proposed by the Directorate proved quite difficult. The plan was for the Directorate to identify children and young people as patients using patient admission data. It was not always possible to identify children and young people who had shared care arrangements in place, in this manner using the data currently available.

By the time this became apparent in early November, the existence of the research had become more widely known as people heard about it through the Minister's office and through contact with HCCA. It was also clear from the first discussions that situations for families varied significantly by disease types.

HCCA therefore proposed that contact be made with different disease advocacy and patient information groups both to identify potential interviewees across a range of conditions and to find differences and similarities between disease groups. A trial interview was conducted with staff from Arthritis ACT, to see if it was possible to gather a collective view of their consumers about the experiences of shared care and this appeared fruitful.

In addition, HCCA and its researchers have had considerable success recruiting individuals to interview from other interviewees, from health professionals, from the advocacy groups and from referrals and direct contact from its members. The Directorate endorsed this change to the recruitment strategy. The Interim Report was provided to the Directorate at the end of January 2020, as set out in the agreement.

Interviews and Analysis

Context of the Stage 3 Research and Interviews

The environmental and social context for the Stage 3 research was complicated. While the researchers continued to recruit people over December and January, the response rate was affected by the Christmas period and January school holidays, as was expected. However, for many families with sick children, the poor air quality from the smoke from the December/January bushfires in NSW meant people were reluctant to participate in face-to-face interviews because their children were unable to go outside to play, while we conducted the interviews. We adapted our interview technique to conduct the interviews over the phone or Zoom during the children's nap or screen time. Dropouts became more of an issue in January/February when Canberra was directly threatened by bushfires. After the fires were over, we conducted more interviews once children went to school. However, before the fire season ended, the ACT population and the world was reeling from the COVID-19 Pandemic and the consequences of the new Public Health State of Emergency which was declared on 16 March 2020 and continues as we complete this final report. Parents were now often trying to work at home with their children, and while a number of people still were able to be interviewed, others nominated to participate and then withdrew.

Around a third of those originally identified by organisations or who had volunteered pulled out or cancelled because of the external pressures upon them. Initially we had addressed potential participants concerns by moving from face-to-face to phone and Zoom interviews. Once the COVID-19 lockdown was in place, we were only able to undertake phone interviews, but a significant number of people who had requested an interview withdrew because they felt too overwhelmed with what they were already handling at home. All of the stresses felt by parents of children were considerably amplified when the child was ill or had a long-term condition and the parents were still trying to keep themselves and their children healthy.

Interviews and Analysis

Recruitment

For Stage 3, we contacted a number of disability and disease specific organisations (called stakeholder organisations in this report) to provide us with contacts for people who were happy to be interviewed. These included:

- Arthritis ACT
- Down Syndrome ACT
- Cystic Fibrosis ACT
- Cerebral Palsy Alliance ACT

- Capital Region Muscular Dystrophy
- People with Disabilities ACT
- Playgroups ACT

As well as nominees from some of these groups, consumer interviewees included those who approached either the Minister's Office, HCCA or were nominated by other consumers/families. We also offered the stakeholder organisations the option of providing us with an overview of their collective experiences of members – those who chose to participate are called stakeholder participants in this report. Their views provided a useful supplement to the voices of individual families, showing that many of the individuals stories were common examples of systemic problems experienced by families, children and young people involved in interstate care.

In addition, we interviewed Suzanne Tunks of the Stella Bella Foundation, a charitable organisation which provides significant support to families with sick children where there is no specific supports otherwise available. The Foundation was referred to by many people as an important support, when there was no-one else.

The recruitment strategy and the various catastrophes which affected that plan resulted in interviews with 12 families and 4 organisations. One of the parent interviews was out of scope, because the care had occurred more than 36 months before the interview, but it provided useful historical context. The families included children and young people with a range of conditions, including but not limited to:

- Leukaemia;
- Osteosarcoma (bone cancer);
- Brain cancer;
- Craniofacial abnormalities;
- Cystic fibrosis;
- Epilepsy;
- Genetic conditions;
- Down Syndrome;
- Musculoskeletal issues; and
- Severe gastrointestinal disease.

Some children were born with conditions and were diagnosed soon after birth. Some had congenital issues where diagnosis was very significantly delayed (up to five years in one case). Some children had their first episode of ill-health when they were two or three years old but continued to have treatment and recurrences over many years, until adulthood. Some children and young people recovered, after a long period of ill-health, some continued to be chronically ill and were expected to need health care for the rest of their lives. Some had conditions which remained life-limiting and unfortunately, some had died.

Families often had other children, and the interstate care experiences impacted heavily on both children and parents. Where the child's needs were intense and/or long-lasting, the financial impact on the families could be catastrophic. They struggled to work and care for their children and travel or live for extended periods of time interstate, sometimes away from all their natural supports. Some families had extended family or friends where their child was receiving treatment but many did not.

Gaps in Recruitment for Interviews

While we reached a range of consumers and families involved with different conditions, it proved difficult to talk directly to children and young people. Those whose parent agreed to ask their child – usually those where the child had recovered and were older or adult – none of these young people wanted to go over their experiences. While it might be possible to do this through a different project, HCCA is concerned that the increased vulnerability and risk to this group would require ethics approval.

Due to our concerns about the higher ethical requirements for research into Aboriginal and Torres Strait Islander consumers, vulnerable groups and culturally diverse families, and the small size of the research cohort, we did not seek specifically to interview families or children and young people from these groups. The specific needs of these people need to be studied separately, but this research provides some starting points.

Young people with mental health issues and eating disorders are not specifically included in this research, because they also raise special issues of vulnerability and the need for ethics approval to be interviewed.

The Interviews and Analysis

The interviews were conducted between December 2019 and April 2020. All participants were sent three documents either directly by the researchers or by their advocacy organisation. The first described the research project, the second talked about the role of participants in the research and the third provided them with ideas for what they may wish to talk about (see Appendix A). As discussed earlier, due to the ever-changing environmental and emergency conditions over the time of the research:

- some interviews were conducted face to face, were recorded and professionally transcribed;
- some were conducted by phone and detailed notes were taken by the researchers and these were transcribed as a record of interview; and
- some were conducted as video conferences over Zoom, where they were recorded and transcribed.

Direct quotes used in this report came almost always from the transcribed interviews but the information in all interviews was used in the description of issues and experiences.

Interviews sometimes took a longer time than expected (up to 2.5 hours in one case). These stories were often very significant events in the lives of family members and children. This meant that, even after a long time, their memories have maintained detail and clarity. For others, the freshness of the experiences also became a time of processing their experiences. Even on phone calls and Zoom conferences which tended to be shorter, the interviews often extended to more than an hour. Often the stories show evidence of significant emotional distress and sometimes, system created trauma. Where children had not survived their disease, there was deep grief, and this appeared to be aggravated by the feelings of confusion and systemic failure they witnessed when they felt they most needed help. HCCA interviewers allowed people's stories to unfold in their own time and most commented that they felt it was the first time that people had actually listened and asked what would make it better.

The transcriptions of the interviews with consumer participants and the stakeholder participants and the earlier interviews with health professional participants were all used in the analysis of issues. These were all then subject to a thematic content analysis to allow us to highlight contextual themes.

Comparing discussions with the individual families and the organisations representing classes of those who participated in shared care arrangements, the themes raised by their experiences showed that these were common across diseases, across families and indeed across the community in the broadest sense. These are discussed below in the section Identified Issues and Recommendations for Action.

Identified Issues

The views of service providers in the health system and the experiences of consumers and families can be very different. While we have sought to gather and triangulate evidence from both directions, in the end the views of consumers are what this research seeks to document.

Interviews were conducted with the families of children affected by a wide range of conditions, to get an overarching view of the issues faced by families and how, and if, these issues were affected by different diagnoses. While there was some variation, particularly in acute versus long-term conditions, many of the challenges faced by families were consistent regardless of diagnosis.

Key issues like access to information, cost of accommodation, the difficulty of the IPTAS process and employment challenges, while shared, tend to have a different emphasis between acute and long-term conditions. With acute conditions, trips to Sydney are more likely to be higher in intensity and unplanned making booking free or subsidised accommodation, leave with work or making sure all the correct paperwork prepared for IPTAS applications challenging.

On top of this families with sudden onset acute conditions usually do not have the time, emotional resources or knowledge to search for the supports they are likely to need. This makes easy access to clear and up to date information critical. In the case of long-term conditions respite care and childcare is not often available which affects a parent's ability to work. When they can work they often use their leave to take regular trips interstate for medical appointments, sometimes multiple times in one week. As the families try and work towards the best outcomes for their children, they randomly stumble across information, supports and resources, rather than these being provided to them at the beginning in an organised and systematic process.

Parents who a have child a with long-term condition also end up with a heavy administrative load. They are often required to manage cross state specialist appointments, any IPTAS or NDIS applications and reporting, navigating their child through the complex interrelationships between the health system, NDIS and allied health services, as well as being the only source of their child's complete cross hospital treatment history.

The consistency of these challenges across diagnostic groups, highlights the poor preparation of the shared care system in relation to the predictable needs of these families. This poor preparation results in a high level of unnecessary chaos for these families and can, in the worst-case, result in unintended harm.

Complexity and Silos

When a child or young person becomes ill or has a condition that requires interstate health care, this can have profound effects on their lives. The health system and people within it focus on the immediate issues at hand, but the family may be facing many consequent stresses and traumas arising directly from the child's need for that care. The health system remains completely ignorant of this broader context of suffering and often seems unable to see the whole family's situation. The suffering for families is significantly increased by having no support to navigate all these difficulties and for the health system appearing to have no clue of the impact of what is happening on their broader lives.

Varying degrees of trauma can be experienced by families and children in these circumstances. For example, these can include major financial difficulties as families cope with reduced income from being unable to work while caring for their child, direct expenses associated with travelling interstate and staying interstate. One parent talked about almost losing their home, because they couldn't meet their mortgage payments on one income. People talked about having to borrow money from their family, having to raise money on crowd funding sites to meet their living expenses, and having to rely on their church or other social clubs to raise money to keep them afloat. These and other individual issues are discussed below – this section looks at the complexity which arises when health care services are unaware of the breadth of the impact of the child's care needs.

There are complexities from trying to manage a family at a distance and where there are important competing demands from other members of the family. For example, an older sibling maybe in their final year of school, and unable to get their parents' direct support because they are dealing with immediate crises of the sick child.

Parents also often talked about the additional stresses caused by schools which did not understand the child's issues or limitations, and pressured a chronically ill child to "buck up". Long absences and staff changes aggravated the disconnection felt by the child and family.

There were also complexities because different parts of the health system did not "communicate" with each other or seek to have good channels of communication when a patient had shared care with another doctor. There was inconsistent advice between doctors and professional turf disputes, both of which put additional on parent or the child and left them in even greater uncertainty.

Some of the bureaucratic silos that caused greatest difficulties were:

- between hospitals and doctors interstate and in Canberra and even sometimes between Canberra Hospital and University of Canberra Public Hospital within Canberra;
- between different health professionals and between public and private providers; and
- between the health care system and the National Disability Insurance Scheme.

Health service providers who took a best practice approach were able to put people in touch with advice and support services which could help them through the reality of their lives at this important time. However, any understanding of this complexity by health providers or the opportunity to actually discuss the complexity of their situation was the exception rather than the rule. There were occasional individuals who took such an approach but almost no examples available from the interviewees where such a holistic approach was embedded in the system. People generally found that when "the good one" went on leave or got sick, then the system failed to meet their needs. This was very confusing, caused great anxiety and further delays in treatment.

Services and Resources

In looking at how to alleviate the challenges for children who receive interstate care and their families, it is important to look at what services exist locally and elsewhere. Many of these services do vital work for these children and families, more detailed descriptions of these services can be found in Appendix B.

However, from our interviews and as noted above, it became clear that parents often only found out about these resources and services through word of mouth from other families and occasionally through hospital social workers or other medical professionals. It is vital that up to date information about these services, as well as the necessary supports needed to access them, is made readily available to all parents. In the words of one of our participants:

> *"…if there are other things out there that are wonderful that are going to really help but nobody knows about them then what's the point of them?" –*
> *Consumer Participant*

Appendix B provides a starting point to build a more comprehensive list of available resources that can be provided to families who require interstate care. A number of recommendations later in this report discuss this issue further.

Available in the ACT

Government (ACT and Commonwealth)

ACT Interstate Patient Travel Assistance Scheme (IPTAS)

Provides financial assistance towards travel and accommodation costs to eligible permanent residents of the ACT who are required to travel interstate for specialist medical treatment that is not currently available in the Territory.

Carer Allowance

A fortnightly supplement of $129.80 if an eligible person gives additional daily care to someone who has a disability, serious illness, or is frail aged.

Carer Adjustment Payment

A one-off payment if the parent/guardian's child under seven years old gets a severe illness or has a major disability. With a maximum amount of up to $10,000 tax free, depending on eligibility and the family's circumstances.

Carer Payment

Income support payment if an eligible person gives additional daily care to someone who has a disability, serious illness, or is frail aged.

ACT Paediatric Palliative Care Service

Nursing-led service based at Canberra Hospital in Paediatrics, it is generally available 9am-5pm Monday to Friday.

Community

Stella Bella Little Stars Foundation

The Stella Bella Little Starts foundation is focused on providing support and services to for children who have a serious and long-term illness, regardless of diagnosis, and their families. They provide Financial Assistance, Bereavement Support, Child Care, Respite, Family Support and run the Little Star Beads and Little Hearts Programs.

Clare Holland House

Clare Holland House (CHH) is the primary palliative care facility in Canberra. It provides a range of palliative services for patient as an inpatient service, at home or in residential facilities. They provide a limited level of paediatric palliative care largely focused on end-of-life palliative care and end-of-life respite.

Rise Above - Capital Region Cancer Relief

Rise Above – Capital Region Cancer Relief, previously ACT Eden Monaro Cancer Support Group, provides financial support to cancer patents in Canberra, Queanbeyan and surrounds (any type of cancer). They help with the many of the costs associated with cancer such as medication relating to current treatment for cancer, chemotherapy, food supplements and food & petrol vouchers and electricity accounts

Camp Quality

Camp quality offers services and programs services made specifically to help children aged 0-13 cope with the daily ups and downs of dealing with cancer. They may be dealing with their own diagnosis, or the diagnosis of someone they love, like a brother, sister, mum or dad. They provide a range of service in and outside the hospital including informational resources, financial support, therapist support, primary school education, kids' camps, family camps, family activities and retreats.

Canteen

Provides support and assistance for young people (12-25) who have been diagnosed or have a parent or sibling with cancer. Canteen provides, resources, counselling, camps and other social activities. They also run the Youth Cancer Services which provides specialist and age-appropriate treatment and support for young cancer patients aged 15-25.

From other Jurisdictions

Accommodation

Ronald McDonald House

Provides free or subsidised accommodation for parents, and sometimes families, with seriously ill children that are required to attend the closest women and children's or children's hospital.

Staying on the Ward

Most hospitals provide the capacity for one parent (no siblings) to stay on the ward with the child unless the child is in intensive or emergency care units like the Intensive Care Unit(s) (ICU) or the Emergency Department. In these cases, most hospitals have a small number of rooms for hire (a nightly fee is charged) for parents whose children are in the more intensive units.

Respite and Palliative Care

Bear Cottage

Bear cottage is a palliative care hospice that specialises in respite and palliative care for children under 18 who have been diagnosed with a life limiting illness. They provide 24hr psychosocial care for the children under their care, on staff they have a paediatric specialist, experienced paediatric palliative care nursing staff, on call general practitioners (GPs) and other support staff like house keepers and a chef. They also facilitate the provision of a range of other allied health care services that are aimed at helping children with life limiting illnesses have the best possible life, these services include Child Life Therapist, Social Workers, Registered Music Therapist, Registered Art Therapist and Physiotherapist.

Additionally, they provide a range of resources, counselling and support services for families to help them through the challenges that caring for a child with a life limiting condition presents.

Other Useful Resources for Reference

'There's no such thing as a silly question: a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition'

This resource developed by InterACT is a booklet aimed at providing general and region-specific information about the challenges, resources and services available for a child living with a chronic illness, disability, mental illness or a life-threatening condition. Currently they have developed versions of the booklet for Victoria, South Australia and Western Australia.

NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) Online Portal

In May 2018 NSW launched an online system for their IPTAAS program. This online portal allows the user to see their current and past (those submitted after the 6th of April 2018) applications, to submit supporting documentation and tax invoices. While it is not perfect and they are still improving it, it provides many features that help to streamline the assistance application process.

http://www.iptaas.health.nsw.gov.au/home

MissingSchool - Telepresence robots in schools

MissingSchool launched a telepresence robot pilot launched in the ACT (and being rolled out Australia wide) with funding from St. George Foundation's Inspire Grant. The pilot places telepresence robots in willing schools to demonstrate that continuous two-way connection is possible between seriously sick children and their classrooms when they are absent, missing school.

Southern NSW Telehealth Program

Telehealth is being used in Southern NSW to help reduce travel costs, improve access to health and support services and improving patient safety by keeping them off the road. Currently tuberculosis support seems to be the major publicly available telehealth service, however the aim of it is to provide specialist support to local health practitioners so that they can provide the care required for their patient's specialist needs closer to home.

Issues from the Interviews

Interviews with Families

> *"...if we're genuine about sending people on this journey we don't put barriers in their way, we should be supporting them and the worst is, I think, we don't really, we don't and that's really tragic…" – Consumer Participant*

The interviews with families raised a number of key concerns in three overlapping areas: practical issues, systemic barriers and personal challenges.

Practical Issues

1. *Financial Insecurity*
   Looking after a child with a long term or life limiting condition under shared care is a full-time job. Most parents do not have workplace conditions that would allow them to take an unpredictable, often extended period off work, or to take leave

with little notice to travel interstate. Many end up having to leave their job to look after their child. This puts financial stress on a family and can even result in the family needing to sell their home to remain financially afloat.

What financial support that can be accessed from Government sources is often minimal and can have conditions which add further complexity for these families.

"Financially, we were okay because of our support, but not many people get that. … And that's why I do advocate for other people. But Centrelink, it was $125 a fortnight between us." – Consumer Participant

"The NDIS doesn't cover the [cystic fibrosis] related costs of families." – Stakeholder Participant

In the case of an acute life limiting condition, both parents often are needed to handle the complexity of care surrounding the condition. Also, in these kinds of cases, they want to be able to spend as much of the child's remaining time with them as they can.

Some have turned to crowd funding to help make ends meet as the current financial support services are inadequate and require an excessive amount of time to apply for and administer. Parents looking after a child at the end of life find that their time is better spent on their main focus, which is of supporting and caring for their sick or injured child.

For parents with children with long-term conditions, the added burden of trying to navigate government support applications and services on their own, while also managing the child's care can be nearly impossible.

"I cried the day the NDIS called me and said she could have some funding because we'd tried so hard to get it and it finally meant we could give her what she needs and we're starting to see the benefits of it now. But if I hadn't of pushed and borrowed more money to get the extra letters and this and that she needed..." – Consumer Participant

2. Accommodation at the interstate location

Accommodation options at the hospitals are very limited. Most only allow to one adult, more rarely two adults and usually no siblings. If siblings are allowed to stay the accommodation itself often may not be suitable e.g. trying to fit a whole family in one room, or not be wheelchair accessible.

Charity or subsidised accommodation in and around the hospitals is in high demand and often cannot be booked in advance or booked for long periods. Families, especially at the time of diagnosis, often have to spend extended periods interstate with little to no warning. In these cases, if there is no charity or subsidised accommodation available or family or friends who can put them up, the cost of accommodation in the areas surrounding the hospitals are exorbitant especially when the unpredictable length of stay is considered.

"And that's the other thing is too with accommodation because [we tend] to go up in an unplanned fashion, Ronald McDonald House and what-not; they're always booked out for the cancer families, and yes, they need the support too, but so do we. But there's never any spaces for us, so I can never take the kids up or anyone else; it's always I'm there, I sleep next to the bed 'cause there's nowhere else, or we pay and I stay somewhere privately, but mostly I just sleep by the bed." – Consumer Participant

There are subsidies available to help with interstate accommodation and travel under State and Territory-based schemes. In the ACT this is called the Isolated Patient Transport Assistance Scheme (IPTAS). IPTAS provides a small stipend of $44 per night for the patient and/or escort to help with the cost of accommodation. In the cases that charity or subsidised accommodation is unavailable this amount falls far below the cost of commercial accommodation in the areas surrounding the hospitals.

"if you don't get into Ronald McDonald House, well, $40 towards your accommodation doesn't really cover much. Especially when you're in Randwick right near the beach and accommodation is not cheap." – Consumer Participant

3. *Isolated Patient Transport Assistance Scheme (IPTAS)*

As noted above IPTAS is available to assist with some travel costs. There are a range of ongoing and incidental costs associated with transporting children to specialist appointments and hospitals interstate in your own vehicle that are not taken into consideration under the IPTAS program.

For a one-off trip these costs can often be absorbed. When a child has a long term or life limiting condition which requires regular trips interstate to ensure the provision of adequate specialist care, these costs add up very quickly. These costs, such as increased vehicle wear and tear, meals and parking costs at or close to the hospitals, add to the general financial vulnerability of these families.

"Parents can't recover a lot of the incidental costs. For example, food can be a problem, both because of the cost and quality of hospital food or living on take away" – Stakeholder Participant

The IPTAS application process is also very laborious, requiring the parents, doctors and other health care providers to manually fill out hard copy paper work for every trip. In the case of acute cases, that require frequent trips back and forward, this process is unmanageable for families.

"There's something called IPTAS. And I believe that a lot of [the costs of travelling] were paid for at the start. Towards the end, I think we just couldn't be bothered claiming them because the process was too hard, and [we] were going so often, so I think we just wore the costs" – Consumer Participant

This process seems to have become more laborious over time, with parents now having to provide receipts from when they leave and when they return. This means for instance that parents cannot fill up their car the day before, if they are leaving early in the morning or the day after, if they return late at night.

"It's changed since we started on it. When I first started it was quite easy. You just had to have the form and at least if you had one receipt, sort of evidence that you travelled, that was okay. Now they're quite strict and they're insistent you get a receipt when you leave [and] when you get back." – Consumer Participant

It was also noted that IPTAS is not available for families whose children are required to follow up with interstate allied health services, such as physiotherapists. This is particularly an issue in cases of post-operative follow up with the allied health services at the relevant children's hospitals.

4. *Navigating the health system*

Families need to know who to contact to coordinate their child's care both in Canberra and interstate. Often it appears that the larger hospitals in Sydney have dedicated staff to liaise and co-ordinate care within the NSW system, but the Canberra arrangements appear more ad hoc and the communication links between the two systems is often poor.

"I would have loved for there to be someone who was like a key worker who just monitored us and helped us to liaise with everyone that was appropriate because half the time I didn't know. 'Should I ring the Sydney Children's Hospital social worker? Should I ring the Canberra Hospital social worker? Should we be having counselling, should we not be having counselling? What financial assistance can we get?'" – Consumer Participant

This is especially important in times of crisis or emergency. These challenges are only heightened in shared care situations, without a key contact person who parents often have to attempt to co-ordinate themselves this. This can result in delayed information delivery and follow-up or treatments not occurring because of treating specialists not communicating.

"… the sleep study wanted the tonsils and adenoids out, and I told the ENT doctor that and they said, no, we do the sleep study first. And I said, well, no, that's not my understanding. And as a result of that, my sleep study for my son got cancelled and so did the surgery because they were both waiting on each other to do their thing first." – Consumer Participant

5. Access to information

There is a lack of clear and easily accessible information about the services available for parents with children in shared care situations. This means that parents often suffer undue hardship because they do not know what services and supports they can access.

"Waverley hospital has some accommodation but finding out about the places can be difficult there is private accommodation available at places like the San but no one tells you." – Consumer Participant

Regarding IPTAS: "it was about the third trip up before anyone actually said anything, and it's not the thing on the top of your mind while your child's having brain surgery; you're just trying to survive." – Consumer Participant

This includes things like interstate accommodation options, IPTAS, financial support, social and practical support, like in hospital meals, and respite care. Not having the information in a clear, up to date and easily accessible format puts the onus of finding out about these services on to parents who are already facing incredibly challenging situations.

"I find it strange that the person that's in the vulnerable position is meant to be the generator of their own support" – Consumer Participant

6. The role of the General Practitioner (GP)

GPs, who should be central to the coordination of a child's care in Canberra, were notably absent from the experiences of the people we interviewed. Where they did feature it was usually in a negative light as a barrier to diagnosis. They were noted for not listening to the parent's concerns or ordering diagnostic tests that were incorrect e.g. a blood test for paediatric brain cancer. When they were mentioned in a more neutral light they were seen as simply a conduit for referrals with no real practical use in managing the child's care:

"I've got a really good GP that I go in and I tell them what the diagnosis is and what the treatment is and what he will prescribe. That's it…. He completely cooperates with that, he doesn't question me." – Consumer Participant

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Systemic Barriers

"Dealing with the health system is like playing a game of Tetris – every time you move there's another block" – Consumer Participant

7. Communication between hospitals

It is unclear where the specific breaks in the communication between hospitals are. However, it is clear from the interviews that there is an issue. Some of the challenges are created by the technical system incompatibility between hospitals and state imaging services, others seem to be because of a lack of communication or of formalised processes around shared care management, for example the lack of dedicated paediatric contact point for remote hospital staff at the Canberra Hospital and others seem to be related to attitude issues and a general unwillingness to be proactive in contacting the interstate care providers.

"They actually didn't have any systems at all to communicate with the hospitals, so it would literally be an MRI would get done, we would then have to wait about two hours for them to burn it onto a CD, then [we] would actually have to go to a post office, put it in an express envelope, send it up to Sydney, and all this while we're waiting on urgent results about our daughter." – Consumer Participant

Because of these issues the onus of managing this communication effectively then becomes the parent's responsibility. They collate copies of their children's scans, test results and treatment summaries including verifying their fidelity and getting mistakes corrected. Many end up building their own patient treatment file for their child that crosses all of the treating institutions so that there is at least one source of truth about their child's condition. This approach while necessary is not always supported by treating physicians as some do not hand over treatment summaries which then leads to gaps in the child's treatment history.

"… I always kept my own hard copies, as much as possible. And even though, the place that they'd send you to in Sydney, I would tell them I wanted a copy of the report, they've never sent it to me. Promised promises, and no delivery." – Consumer Participant

These difficulties in communication can also result in acute care plans and other vital alerts and escalation plans not being on record at Canberra Hospital. This can lead to children with long term or life limiting conditions who have an acute episode being admitted to Canberra Hospital through the emergency department rather than through the paediatric service.

"When we'd take her to emergency, that was our only option, to take her to emergency, they couldn't even put us in a private room. She was sitting next to a kid with gastro... And I'd have to get there, and I'd just have to fight and fight for everything. I said, 'She can't sit in emergency. She has brain cancer.'" – Consumer Participant

Many children with long-term or acute conditions have presented at the Emergency Department in Canberra Hospital and have had difficult experiences, like the experiences quoted above. In one case a child presented at the Emergency Department after a 35-minute tonic-clonic seizure[6]. The Emergency Department (ED) doctor attempted to send the child home without an observation period as the child "didn't meet the criteria" and the ED doctor was unwilling to contact the Sydney specialist for advice. The parents refused to leave. They contacted the Sydney treating specialist to speak to the Canberra ED doctor. In the end the clinical finding was that the child had had a status epilepticus event which is considered a life-threatening episode. The unwillingness by ED and other doctors to contact the interstate treating team was noted by a number of parents of children in shared care arrangements, particularly those of whom the majority of their child's care is managed through an interstate treating specialist or hospital.

Even in cases where the parents are proactive in trying to coordinate a Canberra based interdisciplinary team to co-ordinate with the Sydney treating team to help manage things like post-operative recovery, they have been singularly unsuccessful because the child is not currently a patient at Canberra Hospital. This makes it incredibly difficult to maintain a child's continuity of care in shared care situations or to ensure that a child who has complex post-operative needs can have the post-operative care provided as close to home as possible.

"If you are a teenager, who is seeking to move to an adult neurologist in Canberra, the doctors will probably have not had contact with Sydney Kids Hospital. Sydney Kids Hospital will help as much as possible but the experience of patients is that the information does not seem to make it to the ACT doctors." – Stakeholder Participant

Parents had put great hopes in the *My Health Record* developments but found that important information was often not recorded, that it was not accurate, that it was

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[6] The parent had been told by the specialist in Sydney that a seizure lasting longer than 5 minutes can result in brain damage.

very difficult to get any errors corrected and that clinicians seldom referred to it. In addition, allied health practitioners were unable to add information to it, so in complex situations, where it might have been a useful single point of reference, it wasn't. At the moment, the view of parents was that it was not working as a useful, complete, transferrable record, and was often more misleading than useful.

8. *Education*

There are a number of issues that children who spend long periods of time in hospital face in addition to the direct consequences of their medical condition. One of the most critical for school aged children is the interruption to their schooling and the support for them when they return to school. This is of particular concern where the injury or illness results in disability or learning difficulties. While there are some systems in place aimed at supporting kids with disabilities, they do not cover the needs of children and young people with long term or life-limiting illnesses very well. While some systems and policies may be in place at a Directorate level, the implementation on the ground is often poorly managed and supported. This means that the onus is once again put on the parent to work with the schools, often on a fairly intensive basis, to make sure the needs of their child are being met.

"So the outcome, which was for [him] to live, has been achieved. The outcome for him to have a life worth living, through the school system, has not." – Consumer Participant

Another challenge comes when dealing with kids who have to have interstate care for long periods. In these cases, it is much harder for them to remain connected to and participate in their local school community. This disconnect adds an extra layer of isolation and challenge for these children. There are programs like the Telepresence robots pilot program started in Canberra that are aimed at improving this situation, but they are not yet widely supported.

The "Back on Track" program run by the Fight Cancer Foundation, is aimed at enabling children undergoing long term cancer treatment to continue with their education. The program runs out of a number of interstate hospitals. However it was noted that is not as effective as the parents had expected for kids who get their treatment in Sydney but attend school in Canberra.

For children with life-long conditions challenges with education will often continue into College and University, but with the expectation that the burden of advocacy becomes the soul jurisdiction of the young person themselves. Access to education support is complicated even further when a child or young person has a condition that doesn't have an exact diagnosis, because most educational disability support services and the NDIS require a diagnosis.

9. *Communication issues and Professional Attitudinal Prejudices*

Throughout the interviews, there were numerous examples of medical professionals within the Canberra Health System not listening to, or disregarding the knowledge of parents about their child's condition(s). In some cases, this appears to be linked to diagnostic overshadowing, which is when a person has an initial condition and any other issues raised are attributed to that condition by the medical professionals:

"…with the cleft palate it would have been nice if someone had taken us a bit more seriously about his [drinking] issues … he didn't get diagnosed until he was two and that meant that his speech was adversely affected by that because people just kept telling us it's a Down syndrome thing" – Consumer Participant

In other instances, parents were personally attacked because they had tried other approaches to help their children. This was particularly common during the diagnostic time period when medical professionals would not listen to the parent's concerns about the child's health and the parent was left alone trying to help their child as best they could.

"She just had a go at me 'cause I'd taken her off gluten and tried all the home remedies that you try, and so she just yelled at me for making her gluten free and how dare I withhold those sorts of foods from her and what-not, I was going to ruin her life, and nothing else" – Consumer Participant

In other cases, attitudes about the parents, the child's condition or the fact that the child is in shared care also affected the child's treatment:

"And of course, being a midwife that chose to have a baby at home, I should have known better, so…It was all my fault, that's right, 'cause I caused that genetic anomaly." – Consumer Participant

"[When the parent] expressed concerns when they were intending to send him home without any assessment, the doctor said 'your son doesn't have cancer so why are you carrying on'" – Consumer Participant

"Comments have been made at different times by Canberra Hospital staff that she couldn't really expect care in Canberra because she's chosen to go to Sydney." – Consumer Participant

There were also other cases where it is unclear why the health professional would not listen to the parents. This was particularly evident through the diagnostic phases of a child's care:

> *"…she started having slurred speech. She was really tired. She was very pale. She was vomiting on and off first thing in the morning… And I've had other families who I'm in contact who have said the same thing. They were told it wasn't anything. And then she just kept getting worse and worse, just getting more tired and more slurred. Her face was actually not symmetrical" – Consumer Participant*

Similar issues were reported when children presented at Canberra Hospital because of an acute incident. This is particularly problematic for families with children who are in shared care arrangements as it is often the parents who are the only people who are across all the procedures, diagnostic tests, medication and diagnoses that their child has had.

Personal Challenges

10. The psychological impact on the parents

There are very few supports available for parents to help them process the psychological impact of being the parent a child who has suffered a traumatic injury, or has been diagnosed with a long term or life limiting condition.

This impact is felt even more severely by the primary carer, usually the mother, who is, often quite suddenly, taken from their everyday life to that of a specialist care co-ordinator for their child.

> *"So when you've got to fight that system, fight in this system, try to keep your job, try to keep your husband's job… Try to keep your relationship… Try not to lose your house… Make sure your other kids are okay, with really not a heck of a lot of support." – Consumer Participant*

The physical and psychological cost of this level of constant stress is high. It puts an incredible strain on the individual's mental health, their relationships and the wider family. While some supports are available they seem to be provided on an ad hoc basis by diagnosis e.g. parents for children with cancer, or at a very basic level through the hospitals. Having a child who has suffered a traumatic injury, or has been diagnosed with a long term or life limiting condition is a highly complex psychological and emotional challenge in and of itself for parents. Each parent and child will be affected differently. It is important that we not only have the correct systemic and practical support measures in place but also there is support for the emotional and psychological wellbeing of parents, given they act as the main support and advocate for their child.

"The thing is as well, the kids need the parents to be calm. We can't be calm when we're fighting. And they don't want to see their mum and dad screaming at the doctors because then they don't feel safe. But what else could we have done? And I knew all this while I was doing it. But I had to fight for her." – Consumer Participant

11. Effect on siblings and close family

"With the kids, particularly for her younger brother…he has lots of - he's 10 and he's a bed-wetter and stuff, and there's lots of anxiety around that stuff. Her older brother had lots of anxiety. He – well, he took an overdose in January, so whether he's doing well or not, you can't tell. His older sister just has barely spoken for the last five years, just won't talk to us about anything." – Consumer Participant

One of the issues that was raised multiple times was the effect on siblings of a child who has suffered a traumatic injury, or has been diagnosed with a long term or life limiting condition. The challenges for siblings are multifaceted and vary with age and the type of condition, everything from trying to complete schooling while their sibling is unwell, their parent(s) and sibling being interstate for sustained periods of time with little notice or staying with friends and family for extended periods.

"But [he] has suffered so much. His life – not only losing his sister, but the first three years of his life, like I said, he didn't know where his home was." – Consumer Participant

Systems created to support siblings are ad hoc, relatively uncommon and often diagnosis based e.g. a child with a sibling who has cancer. School systems are also not set up to support children in these situations, not being clear about the possible effect of the situation on the child's sibling and often not having counsellors or staff that are qualified to help. Children with a sibling who is fighting a life-limiting condition have the added uncertainty around if their sibling will survive, forcing them to not participate in things or put their own lives on hold so they can be with their sibling.

"I said to her, 'Darling, why don't you just go to Camp…, it's only a week' and she said to me, 'Mum, what if he dies while I'm gone?'" – Consumer Participant

12. *The psychological impact on the child*

    A number of parents, particularly parents of children who have long-term conditions, raised concerns about the psychological impacts of having a long-term condition on the child themselves.

"[She] has had times when she's been really upset about it and not being able – why can't I, she wanted to go trick or treating again this year, I'm like, "Last year you went and you were really tired." "Oh, please mum, please mum", so "Okay, well how about just a shorter walk?" But having to miss out on things, having to be on the sidelines at the athletics carnival on crutches and watching everybody do stuff, or on those days that you've got pain. That bugs you sometimes." – Consumer Participant

Having psychological or counselling services that align with the child's general health care services and that are designed to help the children navigate the psychological and emotional challenges of having a long-term life limiting condition are critical to helping support the child's quality of life.

"Young people need lots of help with the stresses of daily life, grieving for what they expected to be able to do and yet to be encouraged to do all the things that they still can achieve. At the same time, they also need to learn how to manage their frustration and disappointment and set realistic goals." – Consumer Participant

Interviews with Stakeholder Groups

There are a number of stakeholder groups in Canberra that work closely with, and advocate for, families with children in shared care arrangements, organisations like Cystic Fibrosis ACT, Muscular Dystrophy ACT and the Stella Bella Foundation. While most of the issues these organisations flagged were in line with those raised by the consumers they raised a number of systemic issues which are important to note.

1. *Access to Rehabilitation Services*

   There are some adult services in Canberra but no paediatric services that provide the range of services required to support children with neuromuscular conditions. The potential auxiliary health services needed by people with muscular dystrophy and other neuromuscular conditions are now available at the University of Canberra Public Hospital (UCPH). However they are not currently available unless you get a referral from Canberra Hospital, and when a child is receiving services interstate there doesn't seem to be a way to get that referral to UCPH. Some of these are covered by the NDIS and this is usually through the private sector, s there is no real case coordination for those who need access across a range of allied health and rehabilitation services.

2. *Respite care*

There is a lack of respite care options for parents with children who have long-term or life limiting conditions on top of this they are often not eligible for child care. The Stella Bella Foundation established specialised respite care and occasional care for chronically ill (non-contagious) children in 2017. However there is much more to be done particularly for children with neuromuscular conditions, like muscular dystrophy. It is also highly likely that there is significant unmet need, in addition to the important services offered through the Stella Bella Foundation.

3. *Lack of a holistic approach to care*

Services note the lack of a holistic and contextual approach to care results in a wide range of unnecessary challenges for parents and families. This lack of a holistic approach means services do not consider things like the other services the child requires or the fact that the family is traveling interstate to manage the child's care. This makes an already challenging and chaotic situation even more so.

"one family, whose child needed access to infusions twice a week. However, the infusions area could not book infusions twice a week, so every week the parents had different times and locations, a different process in the hospital and poor coordination when they got there. This added hugely to their stress and isolation as well as making work impossible." – Stakeholder Participant

"I literally had driven up and back on a Monday, and it's pretty much a 6 a.m. to 7 p.m. day waiting for the clinics and that, and I did the same thing on Wednesday. Now, on both occasions, no joke, a doctor looked in my kid's ear for 30 seconds and that was the end of the appointment. I was extremely frustrated that I was told, insistent that I had to come and that somebody else couldn't come and have a quick look. Yeah, it just puts a lot of emotional stress. It's unnecessary to go there for some things that they insist you go up there." – Consumer Participant

There were some examples of specialists, clinics and other care providers that did their best to reduce the travel load on families like offering phone consults or trying to fit in quick follow up appointments on days that they were already traveling up, but these experiences were the exception rather than the rule.

Interviews with Health Service Staff

Interviews with health service staff raised a mix of issues that often differed slightly depending on the area of service provided. Many of these issues were similar to those raised by the families and other stakeholder groups. Issues raised by the health service staff generally fit into two categories, those issues that directly impacted their ability to provide appropriate medical care and systemic issues that affected the families more broadly.

Medical Care

1. *Transmission of information about patient treatment in shared care*

   This is a multifaceted issue. On one side, the paediatric unit head is often notified when patients are being discharged from the interstate hospital to the care of Canberra Hospital e.g. Sydney Children's Hospital. However, the administration for this information at Canberra Hospital is currently handled on an ad hoc basis. There is currently no central role that handles the responsibility of setting up the Clinical Patient Folder (CPF) at Canberra Hospital if one does not already exist. Nor is there a process for adding the appropriate information to the CPF or following up with the patient post discharge to make sure they have received the shared care information pack and any other necessary information regarding shared care arrangements for paediatric care with the Canberra Hospital.

   This can be particularly difficult when a patient is discharged directly from the interstate hospital as the treatment summary may not be sent back to Canberra Hospital Paediatrics, but instead to the patient's General Practitioner. Smoothing out these communication channels is especially important for children who have conditions that are likely to have acute symptoms and may need emergency care in Canberra as they want to avoid sick kids being admitted through the Emergency Department if they do not have to be.

   Due to the ad hoc nature of this process the information is also not often forwarded to appropriate services. For example, the social worker who was working with the family on the Canberra side may or may not be informed when they return from interstate care. Sometimes the information will be passed through from the social workers in Sydney directly. However, this seems to be only done sporadically.

   This is even more problematic for patients admitted directly to the interstate hospital rather than in Canberra, as it means that Canberra Health Services may not have any record of them and/or their possible diagnosis at all. This can result in further frustration and stress for the families as they try and provide the required information. As it is not in the official medical record, the doctors in the Canberra Hospital Emergency Department may not be able to legally or medically act upon it. The lack of information can delay much needed care as the on-call staff will have to go through the standard diagnostic procedures, rather than having the appropriate diagnostic, treatment and contact information in the patient's CPF.

2. *Risks from Administrative Errors*

The level of incomplete records in shared care situations and the accidental loss of records is a big problem.

"We also give the family a copy [of the child's scans to take to the interstate treating team] as well, as a fail-safe, and they take it with them too… [W]e also give them [the family] a copy to keep as well because we are very good at losing things in hospitals..." – Health Services Participant

These losses and incomplete records can result in delayed diagnosis or treatment as well as unnecessary trauma for the child as the Health Professionals repeats unnecessary diagnostic processes because the results of previous tests have not been stored in the child's CPF.

Because of these failures, parents then feel obliged to maintain an accurate and complete copy of their child's treatment history themselves. However, clinicians often disregard the information that parents provide and cause further anguish to parents by not listening. The parents feel stuck between needing to be heard and needing to be calm.

The thing is as well, the kids need the parents to be calm. We can't be calm when we're fighting. And they don't want to see their mum and dad screaming at the doctors because then they don't feel safe. But what else could we have done? And I knew all this while I was doing it. But I had to fight for her. – Consumer Participant

This leads to frustration and real patient safety issues for vulnerable children and young people. It also leads to a loss of trust in health services and can lead to parental hostility. This has been demonstrated in other research on carers contribution to patient safety in hospitals.[7]

"But I've just learnt that you need to speak up and just assume that nobody is doing what they're meant to be doing and follow up all the time." – Consumer Participant

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[7] Merner B. Hill S. Taylor M. "I'm trying to stop things before they happen": Carers contributions to patient safety in hospitals. 2019. Qualitative Health Research, volume 29(10), pages 1508-1518: https://journals.sagepub.com/doi/full/10.1177/1049732319841021

3. *Inter-Hospital and/or Care Facility Acute and Palliative Care Plans*
   Another challenge linked with the issue of inter-hospital and care facility communication is the issue of sharing acute and palliative care plans. The hospital systems do not integrate with each other so it is impossible for a Sydney service to add an acute care escalation plan to the patients CPF in Canberra Hospital. Without a clear contact point in the paediatric unit acute and palliative care plans often do not make it to the Canberra CPF or to the other services that should have it e.g. Clare Holland House. This results again in delays in much needed care and intense distress for the families.

"'My daughter is vomiting everywhere. I need to know what's a safe dose to give her.' And they would just say, 'No, sorry, we can't help you. She's not one of ours yet. They haven't given the proper handover.'" – Consumer Participant

4. *Uncertainty and limitations on access to paediatric palliative care services*
   When a child or young person has a life-limiting illness, but parents are still seeking active care for their child, some then had difficulty accessing palliative care and palliative respite care in Canberra. The perception was that the parents needed to accept their child was dying ad not be continuing to seek active treatment.

   In the case of paediatric palliative care such an approach is considered inappropriate by both Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ), which state:

"Children may remain under the care of their primary treating team, receiving care aimed at a cure in parallel with support from specialist paediatric palliative care through a consultative model."
- From the "National Palliative Care Standards 5th Edition 2018", Palliative Care Australia

"PCA and PaPCANZ support that children may receive palliative care alongside medical treatment aimed at a cure, and can be integrated at any point in the illness trajectory. Some children receive palliative care for a short time, while others are supported for many years. Children differ from adults in many ways and the needs of a child vary considerably based on developmental stage, from perinatal through to adolescence. Predicting prognosis and when they may die can be difficult."
- From the Policy Statement: Paediatric Palliative Care a joint policy statement from Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ)

In addition, the palliative care nurse's assistance is only available in working hours Monday to Friday, is not generally available for home visits and appears to have little flexibility to meet the needs of families.

"the palliative care nurse - she was a beautiful person, but … she would say, 'Yeah, yeah… everything is sorted', but then it wasn't. She was the one who said yes, we've got this plan in place for the weekend. And then she only worked Monday to Friday." – Consumer Participant

"When I first found out there was a paediatric palliative care nurse, I thought she would be there [at home] with [my child] having her last breaths. But apparently no one was going to be with us. We were just going to be taught how to manage the medication." – Consumer Participant

Other concerns were the lack of access to paediatric equipment through the paediatric palliative care nurse and hospital for nursing a child at home.

"when things got really bad, we asked [the Palliative Care team] to help us get some equipment for around the house. They brought over adult equipment, like this is the best we've got. And I'm like, 'Well take it back because it's not useful.' They were like, 'We tried our hardest.' And I'd say, 'Don't worry about it. I'll just try and find stuff from Kmart or Target'" – Consumer Participant

5. *Access to Diagnostic Imaging*

Families noted that access to diagnostic imaging was a significant problem between shared care sites, as was discussed in the consumer section above (6. Communication between hospitals). Medical staff also raised concerns about the ability for treating physicians to access the diagnostic imaging for their patients when it was carried out at another one of the shared care sites. Currently patients under shared care who have diagnostic imaging done in Canberra need to have it burnt to CD and then transported and/or posted to the treating specialist interstate, who then may or may not have the technology to read the CD.

"Yes, I carry the CD in my bag all the time…It's just those little silly things that you go, 'Of course I have a CD in my bag.'" – Consumer Participant

If the scan was done incorrectly this process needs to happen all over again. This can result in long treatment delays or with people attempting to work out ways around the issue. This is so that care can happen in a timely fashion, but the work arounds may not be appropriate or secure.

“Every hospital seems to have a different radiology system. They don’t talk to one another so we print off discs. I will send them fast post up to Sydney…we also give the family a copy as well and they’ll take it with them too. We’ll also give them a copy to keep as well because we are very good at loosing things in hospitals.” – Health Services Participant

6. Paediatric Outreach Nursing

Currently there are no paediatric outreach nurses in the ACT that do in-home and\or at school visits. In a number of cases, patients in shared care have to go into the paediatric day stay unit for small things like finger prick tests for leukaemia, blood pressure checks, in-line antibiotics or burns dressing.

“If you do have a child that has come back from Sydney, the family is exhausted. [If] they just need their blood pressure checked because they have had some cardiac surgery, they have to bring the child in.” – Health Services Participant

In the case of school aged children, these further interruptions impact their schooling and more broadly their parent’s capacity to work. This is particularly difficult when dealing with long term conditions that require regular monitoring or check ins.

7. Specialist Care

As the Canberra Hospital Paediatrics Unit is not a tertiary medical facility the lack of Canberra based specialists is understandable, however it is important to support access to specialists when needed. One of the programs that is aimed at filling this gap is the specialist pop up clinics. Currently there are a number of specialist clinics, such as a neurologist who comes down every four weeks and the neuromuscular clinic, which comes down twice a year for two days[8]. These clinics are in high demand and often have long waiting lists, resulting in some specialists seeing 20 patients a day.

Due to the length of the waiting lists and the intensity of the visits, these often don’t allow parents adequate time with the specialist to ask questions about their child’s condition. Some parents are forced to access the specialist directly at their interstate location. This is particularly true in sudden onset or acute cases or for children that require regular specialist care, as the frequency of visits to Canberra may not meet the requirements for their condition.

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[8] The neuromuscular clinic is a large clinic that includes a consultant specialist, occupational Therapist, Physiotherapist and nurse specialist(s).

> *"…but for those who either can't get into those clinics or they're not available here it's not just as simple as we'll just book you an appointment in Sydney. It's, you know, having to take time off work if you're working. Often, you know, it is too much for just one parent to drive up and back so there is obviously then like two people or one person and a support person, and then it's depending on what time your clinic appointment is, whether there is other things you have to do then that is potentially accommodation. So, what might be a half an hour appointment then ends up being a day or two." – Health Services Participant*

Systemic Gaps

8. Gaps with the NDIS

There were a number of systemic gaps noted with the NDIS that make it more difficult to provide shared paediatric care and make it more challenging for parents whose children receive support through the NDIS. For example, it is not clear who provides the funds for transport to NDIS funded interstate specialists. Post-operative rehabilitation for surgeries related to the NDIS supported conditions are not supported by the NDIS. There has also been a lack of clarity around NDIS support for children who are receiving palliative care. The latter issue seems was clarified somewhat in October 2019 in the *How the National Disability Insurance Scheme (NDIS) and health services will work together* flyer:

> *"Where a NDIS participant has a palliative care plan in place and is not hospitalised, the NDIS will fund supports required as a direct result of the disability where the support assists the participant to undertake activities of daily living. These supports may be provided at the same time as palliative care supports.[9]"*

9. IPTAS Gaps

Staff shared many of the same concerns around the IPTAS programs as families particularly noting, for example, the cost of incidentals like parking that are not covered by IPTAS and the limited availability of charity/subsidised accommodation.

> *"… costs of parking which is in Sydney is a big issue, and is very costly … people report back to us that, I think, the cheapest option is about thirty dollars a day" – Health Services Participant*

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[9] *"How the National Disability Insurance Scheme (NDIS) and health services will work together"* https://www.dss.gov.au/sites/default/files/documents/06_2019/attachment-drc-communique-fact-sheet-health-related-supports.pdf

Another concern that was raised was that the program disadvantages those families who may not have the financial capacity to pay the costs upfront. In those cases, parents may not be able to take their child to see a specialist interstate or may be forced to make other financial compromises that puts the family at risk of further financial difficulties.

10. *Approach to Paediatric Palliative Care with Clare Holland House*

When a child has a progressive and life limiting condition, it is not always clear whether and when a family is able to access paediatric palliative care services and what is provided. In the case of the paediatric staff at Canberra Hospital the understanding is:

"Clare Holland [House] I think offer great service, but you need to be palliative and accept that you are palliative… to be under that service. If you are still seeking very active management for your child you are not necessarily palliative by their definition." – Health Services Participant

In the case of paediatric palliative care such an approach is considered inappropriate by both Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ). There is inconsistency between the approach taken to paediatric palliative care services provided in Canberra and those provided in other states, that are more in line with the guidelines set by PCA and the policy position set by PCA and PaPCANZ. This can lead to a host of access issues, frustration and pain on the side of families.

Recommendations for Action

The following recommendations are based on common suggestions made by families and other stakeholders and health staff who participated in the project. They cover four areas:

- Care coordination
- Information
- Improving hospital and health care experiences for children and their families
- Supporting the family and the child beyond immediate care

Given the range of issues revealed by the research, senior executives in the Health Directorate and the Canberra Health Services should be given responsibility by the Minister to address the extensive unmet needs of families and children receiving interstate care. This must involve a concerted effort to address the issues identified in this Report. This is particularly important for the Canberra Hospital and Health Services to ensure their compliance with the NSQHS Clinical Governance Standard 1.1(b).

Working actively and promptly with consumers, families and health professionals to achieve best practice shared care for the children of the Territory does not involve the costs of building new infrastructure. It requires focussed and creative solutions and kind and caring staff to meet the needs of the children or young people who require shared care. It requires the people working in the system to show compassion and capability to the families that love and care for these children and young people, at a time which any parent would face with dread and be at risk of overwhelm.

The repeated themes of miss communication, disrespect and lack of collaboration within the carer-practitioner relationships that came through in the interviews made it clear that there is a lot of work to be done within shared care arrangements for paediatric care in the ACT. This is particularly important as the current state of the relationships, demonstrated through the interviews, puts them at odds with the NSQHS Partnering with Consumers Standard. The explanatory notes for the standard state:

> *"Effective partnerships exist when people are treated with dignity and respect, information is shared with them, and participation and collaboration in healthcare processes are encouraged and supported to the extent that people choose…. Delivering care that is based on partnerships provides many benefits for patients, consumers, clinicians, health service organisations and the health system.*[10]*"*

With this it is also important to recognise that many children receiving shared care are interacting with the system on a repeated basis. The NSQHS Comprehensive Care

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[10] Australian Commission on Safety and Quality in Health Care. "National Safety and Quality Health Service Standards: Second Edition." 2017.

Standard recognised that meaningful implementation of the standard requires that we recognise and ensure that this continuum of care is well managed.

> *“Although this standard refers to actions needed within a single episode of patient care, it is fundamental that each single episode or period of care is considered as part of the continuum of care for a patient. Meaningful implementation of this standard requires attention to the processes for partnering with patients in their own care, and for safely managing transitions between episodes of care.[11]”*

The following recommendations aim to help improve compliance with the standards, propose ways of addressing many of the needs and issues identified in the interviews and could form a basis for an urgent action plan.

A. Care Coordination

1. Establish an ACT Paediatric Nurse Liaison Service.

A Paediatric Nurse Liaison service would allow the ACT to take ownership of the shared care of children living in the ACT and who need interstate specialist care and ensure continuity of care across state borders.

The role would:

- Provide a single point of contact for interstate care providers;
- Systematise the provision of shared care and inter-hospital communication reducing the risk of children and their families falling through the cracks;
- Provide a systemic mechanism to ensure records and treatment summaries make it into the Canberra health system from the interstate providers; and
- Provide a role that has the time to be proactive in getting information on children being discharged from interstate services, such as hospitals and clinics, including escalation plans etc. from the interstate services.

2. Introduce Patient and Family Navigators.

Dedicated staff could help families and younger patients to navigate the complexities of shared care arrangements. This role would also help to ensure the families have adequate support in developing their own health literacy.

The role would:

- Provide a single point of contact for families and children;

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[11] Australian Commission on Safety and Quality in Health Care. “National Safety and Quality Health Service Standards: Second Edition.” 2017.

- Help to clarify what the role is of the various specialists, units and hospitals;
- Help to identify who has the responsibility for care in different situations;
- Help facilitate communication between the care providers; and
- Help families feel less isolated and frustrated while trying to navigate their way through the hospital system.

3. Establish processes to ensure continuity of care across hospital services.

Continuity of care was raised by both hospital staff and parents from different angles. Consumers reported that children are often seen by whoever is on call. While this is understandable at a systemic workload level, parents expressed feeling as though the medical or other hospital service staff did not have the time to appropriately engage or build a relationship with them. Many noted that often their primary physician only has the time for very quick check ins that left them feeling as though their child may not be receiving the best practice care.

Medical staff noted that there was a lack of dedicated paediatric support resources in areas like social work. They noted that that there are issues, concerns and interstate relationships specific to paediatric cases, that hospital-wide support resources may not be aware of.

Processes will need to address this following:

- Wherever possible make sure that the doctors working in shared care situations have adequate time available to them, so that they are able to maintain good relationships with their patients;
- Look at the current paediatric case load to see if further resourcing may be required;
- Look at resourcing dedicated paediatric hospital support resources for areas like social work so that the skills, knowledge and relationships required for supporting paediatric cases can be developed. This also allows for these support resources to build relationships with these families helping them to identify other areas that support may be required; and
- Ensure that Canberra Hospital is compliant with the NSQHS Standards for document keeping, specifically in regards to the Medication Safety Standards 4.3, 4.6 and 4.12(b).

4. Improve access to integrated multidisciplinary team rehabilitation and disability related services.

When children who have received acute care services in hospital in interstate, they often return home to Canberra and are unable to access rehabilitation and multi-disciplinary medical, nursing and allied health services though UCPH or other Public out-patient or community services. They do not have a referral pathway, into these services. Parents cannot stay interstate for the follow-up care which is received in the major hospitals, because of costs of accommodation and further family dislocation. Therefore, parents have to pay high ongoing costs for private care or do without, which can have very negative long-term health effects for children. The absence of such assistance can delay their recovery or prevent it.

The following issues need to be addressed:

- Referral pathways from interstate hospitals and specialist liaison must be put in place to provide ACT children, whose health needs have required them to obtain acute care interstate, to ensure a seamless transition from acute care or specialist care services interstate to rehabilitation care in Canberra, either with private services or UCPH;
- Parents must be provided with information to enable them to access appropriate public health care multi-disciplinary services easily and quickly for their children;
- Prevalent staff attitudes which appear to see children and families who seek interstate care as “not their business” must be challenged and altered to create a shared focus of care around the child and family as their core business;
- The scope of the UCPH should be expanded to provide regular visiting multidisciplinary physiotherapy or rehabilitation clinics, telehealth rehabilitation and more long term supported axillary services for paediatric clients, particularly those to require regular access to physical and physiotherapy services.
- Where suitable services are not yet available, interstate practitioners might be able to come to visit Canberra with the aim of upskilling the Canberra staff so that they can help provide the day to day support for the paediatric clients in Canberra;
- The possibility of a more regular paediatric neuromuscular clinics should be explored. The current wait times for an appointment and the limited time available for the physicians, means that children with neuromuscular conditions risk further degeneration while waiting. It also means they are much more likely to be required to go interstate for the initial diagnostics, the follow up treatment plans and therapy sessions; and
- Barriers to access for support services and facilities by families and children in shared care situations need to be removed. In some cases, services are constrained by disease or condition specific funding rules, even if multiple conditions require access to similar facilities or services. Canberra is a small community while these services and facilities should be able to prioritise access for their key group, it is important that funding and contracts do not limit access to services or facilities based on specific diseases or conditions.

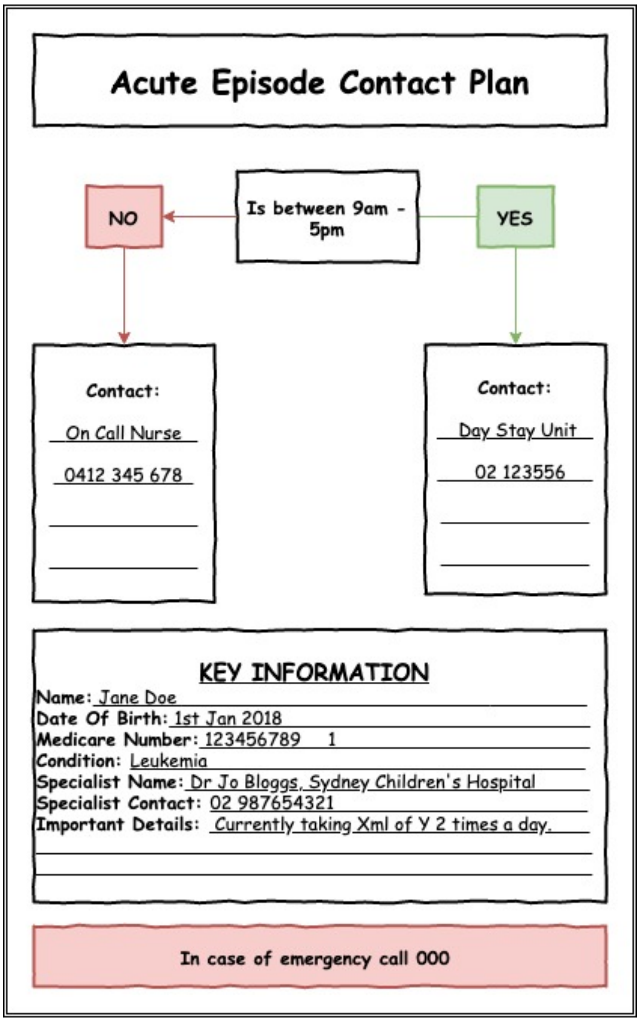
B. Information

5. Develop and introduce an information pack and diary for parents including an online resource.

One of the key challenges raised by parents was having to learn how to navigate the health care system while making sure that all treating physicians and specialists had access to correct and up-to-date treatment information and test results. Most parents ended up building their own version of a patient information folder that they carried with them to all appointments in both states.

The creation of a "Parent's Diary" and a comprehensive parent's pack: this pack would be given at first diagnosis and contain things like:

- An ACT version of the *'There's no such thing as a silly question: a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition'* By InterACT, which provides information about supporting a child living with a chronic illness, disability, mental illness or a life-limiting condition as well as region specific information about services, financial support options, support systems, respite services, contact persons and information on managing shared care arrangements;
- Information on the options available at the relevant interstate hospitals in regards to charity or subsidised accommodation, transport, parking etc.
- An acute episode contact sheet, with the contact information of who to contact if a child has an acute episode, including during and after-hours contacts;
- An acute episode fridge magnet that gives a simple flow chart of who to contact when, so parents have a quick contact list that they can access in a crisis (see Figure 1)
- A copy of their child's official acute episode escalation plan that can be added to the child's CPF at Canberra Hospital and includes information about who their primary care contacts are in Sydney;



Name: Jane Doe
Date Of Birth: 1st Jan 2018
Medicare Number: 123456789 1
Condition: Leukemia
Specialist Name: Dr Jo Bloggs, Sydney Children's Hospital
Specialist Contact: 02 987654321
Important Details: Currently taking Xml of Y 2 times a day.

Figure 1. Example acute episode fridge magnet.

- A paediatrics healthcare pathways guide. This guide would give general information about what the common journeys are through the health care system when you are managing the needs of a child living with a with chronic illness, disability, mental illness or a life-limiting condition, with particular attention paid to where to ask for help if you are struggling to find information along the way;
- A folder or "Parent's Diary" for parents to record appointment information, key contact points and specialist details as well as store official care plans, treatment summaries and test results (including sealable pockets to store scan CDs):
    - This recognises the important role that parents play in the management of their child's care and it also makes sure that the record of a child's treatment is kept with the child. While, ideally, the child's treatment information is available at both the ACT and interstate facility this may not always be the case. Making sure that the parent has copies of the most recent treatment and test information in an officially recognised format will help to alleviate some of the inter-institution communication issues. Especially if it is made clear throughout the Hospitals, including the emergency department, what the "Parent's Diary" is and its role in helping them have the most relevant and up to date information.
    - To do this successfully means normalising the provision of accurate treatment summaries and test results being given to the parents when they have received care in both Canberra and in interstate treatment facilities.
- The development of a supporting Website and on-line community, where information is updated regularly and where parents know where to look, and know they can seek help from other parents would be of great assistance to Canberra parents and their children. Models which are disease specific already exist, but the model could be extended for all services and assistance for children with chronic conditions and using interstate specialist care; and
- Advice and information about the accommodation options available at each of the key interstate hospitals, particularly noting those options that are available in emergency or long-term treatment situations.

6. Provide access to diagnostic imaging for interstate specialists.

Currently treating specialists do not have access to scans they have requested if scans are performed in the ACT. This means that patients are often required to have the scans done, collect a CD then take it manually to the treating specialists or post it to them. This is an incredibly slow, inefficient and insecure way of managing vital healthcare information.

- Provide a system for online access to diagnostic imaging results for interstate specialists who are treating Canberran patients so they can access the scans they have requested in a secure and timely fashion.

C. Improving Hospital and Health Care Experiences for Children and their Families

7. Improve acute incident processes.

It is usually inappropriate for children with chronic and/or life limiting illnesses to have to go through the Emergency Department (ED), due to their often reduced immunity to other acute diseases and the relatively high frequency of their visits. It is important that the process for handling acute episodes be clear to all hospital staff and be communicated clearly to parents.

- In the case of shared care arrangements where the primary care is handled in Sydney, escalation and acute care plans need to be on the child's clinical patient file in Canberra;
- If the patient presents at the ED an alert on the clinical patient file should let the ED staff know that the patient has an acute care plan and direct them to it;
- In the case of children likely to present regularly at Canberra Hospital, instead of discharging them directly from the interstate facility look at a step-down process this would ensure all the appropriate treatment and medical information is transferred and the family will have a chance to get to know the staff and facilities in Canberra;
- Having a fridge magnet or post card that gives the flow chart of who to contact. When a family is going through a crisis episode, it is helpful for them to have a clear and easy set of steps to follow to get help (see example in recommendation 5);
- A process to ensure the emergency and paediatric staff in Canberra are aware of the danger signs of a child's conditions when they present at hospital. This could be through notes on their CPF or through some other hospital mechanism, the key factor is that the staff are aware when the condition has escalated or has had a critical incident so that the appropriate actions can be followed and the interstate specialist treating team can be notified; and
- Ensure the hospital's compliance with the NSQHS Preventing and Controlling Healthcare-Associated Infection Standard 3.6 by improving the ED screening and risk assessment process for children who may be immunocompromised due to their conditions or current treatments. Have appropriate processes for the separation of these children from the boarder emergency care flow where required.

8. Upskill local paediatric staff.

When a child is diagnosed with a condition that requires frequent hospital visits for monitoring or regular injections etc, ideally the routine monitoring and tests should be able to be performed in Canberra.

- In those cases where Canberra Hospital does not have the available skill sets for these sorts of regular monitoring there needs to be a system to upskill local workers where possible. To this end it is important to look at developing a process for a professional-professional supported skill share and/or telehealth program, similar to NSW local care. The program would aim to:
    - Reduce the time Canberra families are required to spend away from home for regular condition monitoring (usually 1-2 days off work for 1-2 people per trip);
    - Improve the regularity of communication between Sydney specialists and Canberra medical staff;
    - Help develop relationships between patients and Canberra based staff. This is particularly important for children whose specific condition meant that they otherwise may not have made a connection with local based care providers;
    - Establish the required patient record transfer so that the Canberra Hospital's CPF contain all the necessary patient information; and
    - Add to the available monitoring and treatment skills available in Canberra.
- In cases where the need for specific forms of treatment or support increases, it is important that Canberra has a process to try and meet these needs locally and that funding is made available for the training and mentoring of nurse specialists or similar to help provide more comprehensive local based specialist care; and
- Increase the time that visiting clinics have available, so that they can provide the required services and also start to help upskill the Canberra Hospital paediatric doctors, nursing staff and any other medical or hospital staff that have contact with these families so that they can be better supported in Canberra.

9. Establish paediatric outpatient nursing role.

Currently parents need to bring in their children to the Canberra Day Stay Unit for routine things like bandage changes, blood tests, blood pressure checks etc. This means that parents often need to take further time off work to bring the child in to the Day Stay Unit. There is a need to establish an outpatient nursing role, who can operate out of the outpatient clinic, and can do home or school nursing visits. This should also be explored for palliative care services for children at home.

10. Implement holistic approaches to care.

Parents regularly noted the that the medical care of the child needs to consider the full family context. This includes things like the cost of regular travel on the family and child; the uncertainty and stress relating to a lack of diagnosis; the emotional and psychological stress of managing the care provision for a child who may be looking at a lifelong or life-limiting condition; the emotional and psychological impact on the siblings, parents and extended family members; and the financial insecurity associated with work pressures competing with the child's care needs. The parents noted that the care and needs of the child are inexorably linked with the care and needs of the family.

A holistic approach needs to address the following:

- Look at the provision of more integrated support services through the paediatric health service;
- Particularly in the case of conditions that are going to require regular contact over a long period of time, ensure that the paediatricians have the time to build positive relationships with the child and their families;
- Making sure that the systems in place put the family and child needs at the centre of any treatment plan e.g. by asking specifically what does the family need; and
- Help to provide links between parents, children and families and other support services, for example disease-specific support agencies.

11. Rethink the role of GPs in shared care arrangements.

Given the poor experiences of families in shared care arrangements with their GPs, it is important that we look at how GPs could be supported in taking a greater role in the coordination of the child's care.

- Given the objectives of the Primary Healthcare Network are about increasing efficiency and effectiveness of medical services and improving the coordination of care for patients[12] they seem to be ideally placed to explore improving the roles for GPs in shard care.

12. Train paediatric and ED staff on the importance of family centred care.

The generally poor experiences of families in shared care arrangements at Canberra Hospital indicates that there is a need to develop a more family centred

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[12] As the role is defined by the Department of Health https://www1.health.gov.au/internet/main/publishing.nsf/Content/primary_Health_Networks

approach to patient care within the service on both the paediatric ward and the afterhours and emergency departments.

- Develop a regular family centred care training schedule that can be delivered at regular rotation intervals to the paediatric and the afterhours and emergency staff. All junior doctors are required to work for a minimum of 10 weeks in the emergency department as part of their intern training. This provides an ideal opportunity for them to learn about shared care as well as how to work with consumers and families in care partnerships. The training should focus on the vulnerabilities and challenges families face and the need for practitioners to respect and listen to families. Initially this program could be delivered through the ACT Paediatric Nurse Liaison Service mentioned above (Recommendation 1).
- It is important to make clear to practitioners the risks of not working with families in a collaborative manner which includes things like poorer outcomes and increased risks of harm to the child, developing hostile relationships with parents and damaging the reputation of the hospital.

13. Review the model of care in paediatric palliative care and the role of the paediatric palliative care nurse.

Currently there seems to be a lot of confusion around what paediatric palliative care services are available, who provides them, how to access after-hours support and what the rules are around accessing them. While the paediatric palliative care position was set up to address other parents' bad experiences, it has been implemented in a manner which seems unlikely to meet its original aim.

The first point of difficulty is in defining what paediatric palliative care is. It is vital that all services providing paediatric palliative care in the ACT have a shared understanding of what it means. Currently the understanding at Canberra Hospital is that Clare Holland House can only provide palliative services when parents have stopped seeking active treatment for their child's condition. As noted above this uncertainty or lack of access is not consistent with national and international definitions of paediatric palliative care.

Some of the issues raised by this research can be addressed immediately, and others may need more exploration through a review. All the issues raised by this research to improve the situation around paediatric palliative care in the ACT should be addressed urgently.

- Clarify the role of Clare Holland House in the supply of paediatric palliative care support in the ACT, including what services are available when and under what conditions e.g. respite;

- Ensure the model of care adopted is fit for purpose through consulting with the parents who have experienced the current model and have suggestions for improvement;
- Consider models for paediatric palliative care that are used elsewhere in Australia and overseas;
- All paediatric palliative care services in the ACT should be in line with the *National Palliative Care Standards*, as noted above;
- For those patients who are under the paediatric palliative care nurse, it needs to be clear who they can contact outside of hours if the child's condition deteriorates. It is also vital that these contact points are aware of the child and that they have access to the appropriate palliative care plan and treatment information whether that be at Clare Holland House or the Canberra Hospital Paediatric Unit; and
- Meanwhile, update the available online information on the role of the paediatric palliative care nurse and what other paediatric palliative care services are available in the ACT.

D. Supporting the family and the child beyond immediate care

14. Improve current ACT Interstate Patient Travel Assistance Scheme.

Currently the IPTAS system is an outdated, essentially paper-based system that parents generally find out about accidentally and does not represent the true cost of interstate travel, especially for those parents who have to manage frequent trips interstate.

Unlike its interstate counterparts, ACT IPTAS provides minimal accommodation assistance of only $44 per night. While this is very helpful when families can access Ronald MacDonald House or hospital subsidised accommodation, there is a minimal amount of this available. There are also limits on how many people can stay, which means if the mother has a baby or other young child, and needs the assistance of the other parent, there is no subsidised accommodation of this kind available. The accommodation allowance is of small assistance to the majority of families who end up in rented accommodation, AirBnBs or local hotels, which is an enormous financial and human burden for families, particularly where the child needs to spend extended times in hospital. There is also no assistance for private accommodation.

- Review the current IPTAS reimbursement amounts to bring them in line with the real cost of interstate travel for specialist care, including parking and

vehicle wear and tear, especially for parents who have to support frequent travel;
- Review the current IPTAS reimbursement application flow and look at streamlining it especially for those who require frequent interstate travel;
- Look at ways of streamlining the application process for kids whose condition require frequent interstate travel for the same condition e.g. a specialist letter that covers them for 6/12/24 months;
- Look at the incidental costs incurred by families, e.g. food costs, and how they can be offset either through improving facilities at the hospitals, working with community groups or providing reimbursement; and
- Review accommodation support, to either provide more cheap accommodation for families or to increase assistance available, especially when families need extended accommodation.

15. Explore options to make more lower-cost accommodation near shared care hospitals available or to increase the IPTAS subsidy to a level reflective of the real costs.

Lack of affordable accommodation near shared care hospitals interstate was repeatedly raised as an issue by almost all interviewees. The ACT Government should explore options for and advocate for low-cost accommodation for families located near the major paediatric shared care hospitals interstate, through government to government discussions. Given that the investment in increasing the provision of low-cost accommodation for families in these areas will benefit more than just ACT residents, this is an excellent opportunity for a collaborative effort between the states and territories to help support these families.

If this does not result in greater availability for lower-cost accommodation, and perhaps until this is explored, IPTAS accommodation allowance should be increased to a level which is more realistic of the actual costs, and be available for a broader range of accommodation options.

16. Enhance the range of support services for families.

When a child is diagnosed with a chronic illness, disability or a life-limiting condition, there is a much larger impact on the family than in other cases. It is important that the family have access to a range of free or highly subsidised services that can help them work out the broader impact of what the diagnosis means for them and help them to work out plans to help manage the situation. Services like:

- Financial advisors who can help them work out their financial situation before they end up in financial difficulty;

- Social workers or community support workers who can help them navigate the maze of government support options and help them apply for the correct supports; and
- Regular counselling or therapy sessions that can support them while they work through the wide range of issues that a situation like this can raise and help them to develop the skills to get through the challenges that they are facing.

17. Improve support for schooling.

Children and young people with chronic, long term or life-limiting conditions are already struggling enough with their education. Helping them stay connected to their local school communities is vital, particularly where they experience long periods of interstate care. It is also important to provide the appropriate support for the kids and teaching staff as the kids return to school so that they can be supported appropriately.

- Develop support for telepresence robots in ACT schools to help sick children stay connected;
- In cases were telepresence robots cannot be provided, look at other internet supported “dial-in” learning, that allow the children to “dial-in” for even an hour a day to help them stay connected with their school community;
- Develop teacher and child friendly resources that families can share with the schools to help explain the situation and highlight challenges that may arise; and
- Look at improving processes so that the child’s school and teacher(s) are resourced appropriately so that they can provide the necessary supports for the child. This could include things like information and resources, preparatory meetings with medical professionals and parents etc.

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Appendix A: Revised documents

Participant Information Sheet for the Kids Interstate Shared Care Project

Consumer and family experiences and expectations of accessing interstate specialist care

You are being invited to take part in a Quality Improvement project, called for short – *the Kids Interstate Shared Care Project*.

Your participation is voluntary. This means that you do not have to take part, and there are no consequences to you if you choose not to take part.

Before you decide to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully.

Why is this study being done?

The ACT Government has committed to better supporting families in coordinating care between interstate services and services in the ACT.

As part of this commitment, the ACT Health Directorate has asked the Health Care Consumers' Association (HCCA) to document the experiences of consumers and families receiving interstate specialist care.

HCCA would like to hear from consumers and families in the ACT who have travelled interstate for specialist paediatric care. In particular, we'd like to hear their perspectives on:

1. what works well
2. what they find/found difficult
3. what improvements they think would make a real difference.

HCCA will provide a report on the findings, with recommendations, to the ACT Health Directorate.

HCCA are funded by the ACT Health Directorate to undertake this study.

The Health Care Consumers' Association (HCCA) was incorporated in 1978 and is both a health promotion agency and the peak consumer advocacy organisation in the Canberra region.

HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- *consumer representation and consumer and community consultations;*
- *training in health rights and navigating the health system;*
- *community forums and information sessions about health services; and*
- *research into consumer experience of human services.*

What is involved in the study?

If you agree to participate in the study a staff member from HCCA will contact you to arrange a time to interview you about:

- Your experiences relating to having to go interstate to get specialist care for your child;
- How ACT services could best care for your needs based on your experiences.

The interview will take about an hour and can take place by telephone or in person at the HCCA office in Hackett or another suitable location. Participants who travel may be eligible for reimbursement for travel costs. You will receive an Interview Guide before your interview to help you think about your experiences. You will be in control of what is discussed at the interview and you are able to stop or pause the interview at any time. If you don't want to answer any question, you can say you don't want to.

With your permission, your interview may be recorded and transcribed. If you want to check the transcription you can.

Are there any risks?

You may experience emotional discomfort or distress when reflecting on your experience. It may also inconvenience you to attend an interview. To address this, the interview will be arranged at a time and location that is convenient to you. The Interview Guide explains the scope of the questions you will be asked and you will be in control of what is discussed at the interview. You are able to stop the interview at any time and/or withdraw from the study. If you do experience emotional discomfort or distress, you may wish to contact Lifeline on 13 11 14.

What about confidentiality

If you consent to participate in this study HCCA will keep your name and contact details on record to arrange the interview. This information will be deleted at the conclusion of the project.

If HCCA takes an audio-recording of the interview, these recordings will be stored on a secure computer server, with one back up recording stored on an external hard drive which is stored in a locked filing cabinet for the length of the study. The audio-recordings will be destroyed after they have been transcribed. HCCA will transcribe the audio-recordings, removing any identifiable text, and will store a copy of these on a secure computer server, separately from your details. HCCA will provide ACT Health with a copy of the de-identified transcripts and these will be stored on the ACT Health secure server for a minimum of seven years in accordance with ACT Government Records Disposal Schedule.

De-identified information from this study will be included in a final report that will be shared with the ACT Health Directorate and may be made public following ACT Health Directorate approval.

Questions or concerns?

If you have any concerns about the conduct of the research, please contact the Executive Officer of HCCA, Darlene Cox on (02) 6230 7800. If you have any questions about the research or the interviews, please contact the lead researcher, Dr Fiona Tito Wheatland at 0412 172 876 or via email at fionatitowheatland@gmail.com

ACT Government | Canberra Health Services

HealthCare Consumers

Kids Interstate Shared Care Project

Interview Guide

The purpose of this interview is to seek information on your experiences as either a family member, consumer or advocate for families where their children experience shared interstate care. The focus is for you to tell your own story and give your ideas about what worked for you and your child and what didn't. It also provides you with an opportunity to tell us how you think it may have been made a better experience for you.

These are some ideas for you to think about before the interview.

Your story

- What led to needing to access health care interstate for your child?
- When and how long did you need to access care for?
- What has been your overall experience with accessing care interstate and in the ACT? Is there anything that you'd really like to talk about, or that you'd like to start with?

Finding out about your experience

- What are the main difficulties in coordinating care interstate and in the ACT?
- Is or was anyone helping to coordinate your care either interstate or in Canberra?
- How much time does/did it take to coordinate the care?
- What is involved in coordinating the care?
- What are the costs of travelling interstate for specialist care?
- What is the impact on your life – family, schooling, friendships, work?
- Do/did you feel like you were well informed and supported? Why/not?

Accessing services

- What services do you use or have you used?
- Which services did you find particularly valuable or useful?
- What services do you think should be available in the ACT?
- What do you think should be the service priorities for the ACT Government?

Improving things for kids and families

- If you could have more help, what would it be?
- Are there things you think should be different or improved?
- What would a good system look like?
- Is there anything else you'd like to say about your experiences?

KIP2-2020

Consumer and family experiences and expectations of accessing interstate specialist care

Kids Interstate Care Project

Sometimes, when children and young people become ill in Canberra, they need specialist services interstate, especially from specialised children's hospitals in Sydney, such as Sydney Children's Hospital in Randwick and the Westmead Children's Hospital.

This is because the ACT Paediatric Service cannot provide "tertiary" level services for children. However, often parts of their care is also provided in Canberra. Coordinating the appropriate services for their kids can be a heavy burden on families at an already difficult time for the family and the child or young person.

The ACT Government has committed to better supporting families in coordinating care for their children between interstate services and services in the ACT.

Health Care Consumers' Association (HCCA) has been asked by the ACT Government to document the experiences of consumers and families, who are receiving interstate specialist paediatric care.

Beyond a description of what exists at the moment to assist families, there are three main parts of the project:

1. Background discussions with stakeholders, such as doctors, nurses, and social workers who care for children, while they are in Canberra;
2. Background information from health consumer groups who have many members with experience of interstate specialist paediatric care; and
3. Interviews with people whose child has received care interstate and in Canberra for their children.

HCCA is listening to the voices of consumers and families in the ACT who have travelled interstate for specialist paediatric care to find out about their experiences. We want to know:

1. what works well
2. what they find/found difficult
3. what improvements they think would make a real difference.

HCCA will provide a report on the findings, with recommendations, to the ACT Health Directorate.

HCCA are funded by the ACT Health Directorate to undertake this study.

For further information contact Fiona Tito Wheatland on 0412 172 876.

The Health Care Consumers' Association (HCCA) was incorporated in 1978 and is both a health promotion agency and the peak consumer advocacy organisation in the Canberra region.

HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- *consumer representation and consumer and community consultations;*
- *training in health rights and navigating the health system;*
- *community forums and information sessions about health services; and*
- *research into consumer experience of human services.*

Appendix B:

Research Background Paper for HCCA Research Project on Children receiving specialist care interstate

Prepared by
Anna Tito

Research Background Paper Contents

ACT Interstate Patient Travel Assistance Scheme (IPTAS)

Eligibility[1]

The primary eligibility for criteria for ACT IPTAS is:

- The patient must be a permanent resident of the Australian Capital Territory[2].
- Medicare eligible patients or Medicare ineligible asylum seekers.
- The Referring Medical Practitioner must be from the ACT or Queanbeyan.
- The patient must be referred to the nearest location within Australia for Specialist treatment[3].
- The patient must have a current referral for a Specialist medical service that is not available in the ACT. This is required every 2 years for regular travellers.
- Treatment is not part of a workers' compensation, damages or third-party claim.
- The patient must claim the maximum available benefits from their private health fund first.
- The treatment/services are registered for use by the Therapeutic Goods Agency in accordance with national guidelines.
- Veterans or War Widows who are not eligible for assistance from The Department of Veterans' Affairs Repatriation Transport Scheme.
- All claims must be submitted within six months of travel.

Exclusions[4]

Benefits are not payable under ACT IPTAS for:

- General medical treatment given by general practitioners and allied health professionals such as psychologists, physiotherapists and speech pathologists.
- General dentistry such as dental extractions.
- Seeking a second medical opinion.
- Inter-hospital transfers.
- Travel by ambulance, air ambulance or any other form of emergency transport.
- Travel or commercial accommodation costs where benefits may be or have been provided through the Department of Veterans' Affairs Repatriation Transport

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[1] Eligibility criteria extracted from ACT Interstate patient travel assistance scheme, Guidelines for Medical Officers & Consumers, Updated 1 July 2017

[2] It is not clear how this should be established for those under 18 the listed acceptable proofs are registration on the electoral roll, a current driver's licence or utility accounts or rental receipts relating to a person's usual place of residence.

[3] ACT IPTAS is not obliged to reimburse costs where the patients/Referring Medical Practitioner chooses to bypass the nearest Treating Specialist. If a patient or referring doctor is unsure who is the nearest Treating Specialist they must contact the ACT IPTAS Office. There are special circumstances where this requirement can be bypassed for medical grounds or if a specialist service is not available at the nearest location, these details will need to be added to the application by the referring medical practitioner.

[4] Exclusions information extracted from ACT Interstate patient travel assistance scheme, Guidelines for Medical Officers & Consumers, Updated 1 July 2017

Scheme, other Commonwealth/Territory Government Schemes, Territory and Employer Schemes, Third Party Insurance or Work Cover / Workers' Compensation claims.
- Hospital-related costs, including private hospital inpatient accommodation costs.
- Specialist medical and/or oral health surgical treatment for injury or illness incurred during business or recreational travel.
- Meals, taxi fares, public transport (including bus, inner-city rail, light rail, ferry), tolls or parking fees.
- All claims submitted after six months of travel.

Benefits[5]

To claim reimbursements there are a number of things to note:

- The claim is made within 6 months of the travel.
- Original tax receipts are presented (Credit card receipts are not accepted).
- In the case of private vehicle transport, a fuel receipt must be final receipt on return to Canberra (ie: fill up before you leave Canberra and on your return to Canberra fill up again and submit the second receipt to show true account of total fuel used for return trip).
- A maximum of one night prior and/or post medical treatment/appointment will be paid on the advice of the Referring Medical Practitioner[6].
- A sperate application form must be completed for each return journey of the patient.
- Parts A, B & C of the form must be completed, Part C must be completed prior to the patient's return and include the interstate specialist's or authorised representatives' signature to provide evidence that the travel has occurred.

Table 1: Benefits[7]

Travel benefits	*From 01 July 2016**	*From 01 July 2017**
Private vehicle *Fuel costs only*	Rebate up to the amount specified below: (return) Sydney $117.68 Melbourne $261.50 Adelaide $487.35 Brisbane $536.08	Rebate up to the amount specified below: (return) Sydney $110.00 Melbourne $220.00 Adelaide $300.00 Brisbane $440.00
Coach	(return) Sydney $88.25 Melbourne $156.91 Adelaide $284.09	(return) Sydney $90.00 Melbourne $160.00 Adelaide $290.00

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[5] Information extracted the IPTAS Claim form

[6] It is not clear how this point affects those escorts whose patients are required to stay interstate for long periods.

[7] Table Extracted from the IPTAS Claim form

	Brisbane $376.79	Brisbane $390.00
Rail	(return) Sydney $120.05 Melbourne $225.84 Adelaide $251.99 Brisbane $251.99	(return) Sydney $125.00 Melbourne $230.00 Adelaide $260.00 Brisbane $260.00
Patient and/or Escort (Including where patient is admitted to a hospital)	Maximum amount: $42.78 per night each patient and/or escort (commercial) $13.08 per night each patient and/or escort (private accommodation)	Maximum amount: $44.00 per night each patient and/or escort (commercial accommodation providers only) Private accommodation is no longer supported

Escorts

- Patients under 18 years of age are eligible for an escort irrespective of their medical condition
- Two escorts may be considered if the child's condition is considered life-threatening
- Escorts who are required to remain with the patient interstate for extended periods of time may be eligible for financial assistance for return travel to attend to personal/household needs. This will be assessed on a case by case basis up to a maximum of 2 return journeys (by road, rail or bus) per month.

Air Travel

Air travel has a whole host of rules and exemptions as a quick summary these are the basic rules for Air travel under the IPTAS:

- Under ACT IPTAS reimbursement of fares is at economy surface level using rail or coach services, unless the Referring Medical Practitioner or Treating Specialist certifies that the patient has a specific medical condition that requires them to travel by air.
- The need for air travel must be provided by the Referring Medical Practitioner or Treating Specialist in Section B of the ACT IPTAS Form.
- Approval for air travel must be gained form the ACT IPTAS office prior to travel.
- In most cases air travel should be booked through the ACT IPTAS office

Ronald McDonald House

Information gathered from the Ronald McDonald House website (https://www.rmhc.org.au)

Eligibility

Eligibility seems to vary slightly depending on location and there is no concrete list of eligibility criteria though all seem to be for accommodation for parents with seriously ill children that are required to attend the closest women and children's or children's hospital. Across all locations priority is given to families whose children have been recently diagnosed, seriously injured or who require emergency treatment. However specific locations have other eligibility criteria and priorities for example:

- Ronald McDonald House Orange, Canberra, South Brisbane and Parkville also prioritises families of premature babies.
- Ronald McDonald House Westmead gives priority to families who live further from the hospital.
- Ronald McDonald House Westmead, South Brisbane and Monash also support mothers going through high risk pregnancies.
- Eligibility to stay at Ronald McDonald House QLD Children's Hospital is determined by medical and social need and is authorised by the PICU team at QLD Children's Hospital.
- Ronald McDonald House Adelaide requires an initial referral from the patient's local doctor, specialist, social worker or patient travel office for the initial stay.

All of these eligibility requirements and priorities are based on availability and it is not clear from their site what the availability of their beds are like.

Fees

Ronald McDonald House state they are free for eligible families of seriously ill children however a parent's stay at the facility may require then to claim financial support towards accommodation and travel from the relevant government transport assistance scheme. They say they gave team members that are happy to help assist with the application process. It is unclear from their online resources when parents are getting assistance through reimbursement programs like the ACT IPTAS if the parent needs to pay the amount upfront to Ronald McDonald House and then get reimbursed for the expense through the government reimbursement service.

Ronald McDonald House, Randwick

- New South Wales residents: Cost: $60 per room, per night for Hospital outpatients and $43 per room, per night for Hospital inpatients.
- NSW residents have access to IPTAAS bulk billing for families staying seven or more nights.

Bear Cottage (NSW)

Eligibility

Under 18 years of age, diagnosed with a life-limiting[8] illness. Referrals can be made by anyone involved with the family including medical officers, community nurses, social workers or the family themselves. Priority of admission is given to End-of-life care[9], Emergency admission for symptom management, Respite Care – emergency and Respite Care – Booked.

Emergency referrals can be made at any time by contacting the Nursing Unit Manager or after hours through the nurse in charge. Children requiring end of life care will be given immediate priority & admission can be arranged within hours if needed.

They take referrals from anywhere, regardless of geographic location or primary care provision location.

Process[10]

- Initial referral is taken by the Clinical Nurse Specialist and the child's condition is discussed.
- Following this both medical and family referral forms are sent to the family or the team most involved in the child's care.
- Once Bear Cottage receives these completed forms the referral is discussed at the weekly intake meeting.
- The family are informed of the outcome following the meeting and if accepted, a booking can be made at this time.

Services

- Respite;
- Support for family through condition development, including pain and symptom management;
- Play, music and art therapy;
- Specialised camps and activities for children;
- Camps and activities for family members;
- End of life care; and
- Bereavement care though their 'Footprints in the Sand' program.[11]

A child can stay at Bear Cottage up to four weeks booked respire a year (dependent on availability). Allied Health services available at Bear Cottage include Child Life Therapist, Social Workers, Registered Music Therapist, Registered Art Therapist and Physiotherapist[12].

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[8] Life-limiting means that the child will not survive into their adult years.

[9] Where death is imminent and expected to occur at Bear Cottage.

[10] From Bear Cottage Website

[11] From Bear Cottage General Information Flyer

[12] From Bear Cottage Allied Heath Flyer

Social Work support and counselling available for the family through respite admissions, when back home, into end of life and bereavement[13].

They provide 24hr psychosocial care. On top of the notes allied health professionals they also have on staff a Paediatric specialist, experienced paediatric palliative care nursing staff, on call GPs and other support staff like house keepers and a chef.

Cost

Nothing. Families do not pay for any of the services they receive while staying at Bear Cottage[14].

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[13] From Bear Cottage Allied Heath Flyer

[14] From Bear Cottage General Information Flyer

Stella Bella Little Stars Foundation[15]

The Stella Bella Little Starts foundation is focused on providing support and services to for children who have a serious and long-term illness, regardless of diagnosis, and their families. They provide Financial Assistance, Bereavement Support, Respite, Family Support and run the Little Star Beads Program.

Little Star Beads Program

The Little Stars Beads Program is a program designed to help add a more positive light to the difficulties for children that have long term medical care. It is open to children 0-12, who are diagnosed with a serious long-term illness and require regular medical treatment. The Little Stars Beads Program offers children little rewards for their medical procedures in the form of unique beads. The beads are strung together to create a string of beads that tell the story of the child's personal medical journey (See https://stellabellalittlestars.org.au/our-beads/ also image below).

TINY LITTLE STAR BEADS

List of Procedures and Events and their Matching Beads

Admission to NICU
Blood tests
Blood transfusions
Breathing on my own
Cannulation
Central line insertion
Commencing long term medication
CPAP
Diagnosis
Discharge
Emergency flight
Extra long stay (30 days)
Extubation
First bath
First breast or bottle feed

First cuddle
Imaging scans *including MRI and CT*
Infusions
Injections
Intubation
Lung function tests
Milestone
NG Tube insertion
NG Tube removal
Oxygen
Significant weight gain
Special Procedure (surgery, tests etc)
Special Occasion in Hospital
Super brave day
X-ray

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[15] Information gathered from https://stellabellalittlestars.org.au

Stella Bella Children's Centre

Stella Bella Children's Centre opened in March 2017, it is an all-inclusive childcare facility offering mainstream childcare rooms, and a specialised respite and occasional care unit for chronically ill (non-contagious) babies and children, aged 0-5.

Little Hearts[16]

Little Hearts is a new initiative by the Stella Bella Foundation run with a dedicated group of parents of children with chronic heart conditions, who have had long stays at the Children's Hospital Westmead, in the PICU, Grace and Edgar Stephens wards.

Little Hearts goal is to:

- provide a range of supports to families of children with CHD who require ongoing surgery, hospitalization and/or who have a palliative diagnosis
- provide a support network for families who have lost a child to CHD and
- provide support to families who have received an antenatal diagnosis of CHD.

In the next 12 months they aim to:

- Provide vouchers for food, petrol, and other necessities directly through the Edgar Stephens ward to families with children who have a severe CHD or complex medical diagnosis who are struggling financially
- Raise funds to provide small grants for heart families who require assistance with household bills, crisis accommodation, medical supplies and more
- Provide a variety of supports for families with a child who has a palliative diagnosis
- Explore opportunities to provide meals on the ward for parents such as fresh food and freezer meal sponsorship
- Set up ongoing friendship and support for families who are regularly in and out of hospital and have children who have a high care or palliative diagnosis.
- Organize family events, outside of hospital, in Canberra and Sydney to help families build on their support networks.

> *"Being a hospital family is tough. There is often so much pain, uncertainty and stress with having a child with a severe or critical diagnosis in hospital. Many children face very tough health journeys and face multiple surgeries and medical interventions.*
>
> *Meanwhile, life goes on and families still have to work out how to juggle competing priorities – other children, relationships, running households and paying bills.*
>
> *Most people think there is a massive support network around long-term hospital families, but the reality is very different. A parent usually stays on the ward to be close to their sick child. They have often come to the hospital in an emergency – if they are lucky with an overnight bag. They have the concern of other family priorities (sometimes the high cost of relocating other children to nearby accommodation). The hospital is not able to*

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[16] Information Gathered from https://stellabellalittlestars.org.au/little-hearts/

provide meals for parents and one of the most difficult things that parents struggle with is providing themselves with basic essentials, such as meals and toiletries.

Families also struggle to find the means to celebrate and mark special events and milestones – which is such an important thing to do for all children but especially important when you may not know your child's future.[17]*"*

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[17] Quote from https://stellabellalittlestars.org.au/little-hearts/

ACT Paediatric Palliative Care Service[18]

Nursing-led service based at Canberra Hospital in Paediatrics.

Services

The ACT Paediatric Palliative Care Service claims to aim to support children with life-limiting illnesses to live as well as possible, and provides[19]:

- Clinical and consultative services;
- Support for staff in hospital medical units, metropolitan and regional health service centres;
- Coordination of services and case management;
- Education in the specialty of paediatric palliative care; and
- Care wherever the child and family are, including in the home, in the community, and in hospital or hospice.

However Palliative Care ACT states that "A child's treating paediatric team usually manages that child's palliative care in the ACT.[20]" It is unclear how this statement links with the ACT Paediatric Palliative Care Service claims.

Referrals

Referrals are accepted from health care professionals across the care spectrum, and families may also self-refer, with subsequent contact made with treating teams

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[18] This is the entirety of the information available in regards to palliative care for children in the ACT.

[19] https://palliativecare.org.au/act-paediatric-palliative-care-service

[20] https://www.pallcareact.org.au/organising-palliative-care/

World Health Organisation definition of Palliative Care for Children

"WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.[21]"

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[21] https://www.who.int/cancer/palliative/definition/en/

Sydney Hospitals Parent Accommodation Options

Sydney Children's Hospital, Randwick[22]

Staying on the ward

- Only one parent or carer (no siblings) can stay on the ward overnight
- Parents can sleep in a recliner/sofa chair
- Parents need to be up and dressed by 7:30am with recliner/sofa chair folded away
- Siblings only allowed to stay in exceptional circumstances
- A number of wards have parent retreat areas for parents to sleep in (they must as the Nurse unit manager)

Parent Hostel Accommodation (ICU)

- Parent only (no siblings[23]) of children admitted to the ICU
- Need to check availability as it is limited
- Cost:
    - Patients, parents and carers who live within 100kms of the Hospital – $20 per room, per night.
    - Patients, parents and carers who live more than 100kms from the Hospital – $43 per room, per night.

Local hotels and Motels

- Avoca Lodge – Starting at $103-202 per night[24]
- Avonmore on the Park - Starting at $135-209 per night[25]
- The Blenheim Randwick - Starting at $143-337 per night[26]
- The Centre B&B - Starting at $90 -175[27]
- Randwick Lodge - Starting at $124-245 per night[28]
- High Cross Park Lodge - Starting at $97-216 per night[29]
- Coogee Bay Boutique Hotel - Starting at $161-449 per night[30]
- Crowne Plaza - Starting at $179-415 per night[31]
- Perouse Lodge - Starting at $113-223 per night[32]

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[22] Information from the Sydney Children's Hospital flyer "HANDY HINTS FOR YOUR STAY IN HOSPITAL"

[23] Except for breastfed babies – from website

[24] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[25] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[26] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[27] From the Centre Bed & Breakfast website https://www.thecentre.com.au

[28] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[29] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[30] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[31] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[32] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

Westmead

On the Ward

- Only one parent or carer (no siblings) can stay on the ward overnight. Except in Paediatric Intensive Care Unit (PICU), the Neonatal Intensive Care Unit (NICU), the Emergency Department and Hall Ward.
- Most wards have two parent rooms (for one or two people) which are allocated by the Nursing Unit Manager (there is a nightly fee charged[33]). Availability of these rooms is very limited and a number of factors are considered when a room is allocated[34].

Parents Hostel

- The Parents' Hostel on level two has a small number of rooms that can sleep up to two adults (no siblings[35]).
- There is a fee per room per night[36].
- Priority is given to families with children in PICU and NICU.

Westmead Hospital Overnight Rooms[37]

- these rooms are to be used for emergency situations only
- availability of rooms is **not** guaranteed, and rooms cannot be secured before arrival
- rooms are available via negotiation with ward staff.

Cost

- $43 per room per night
- $50 key bond which is refunded

Casuarina Lodge[38]

This is only suitable if the patient is over 16 or if it is the only the parents using the accommodation as **Children under 16 years of age are not permitted to stay at the Lodge.**

- Situated in the grounds of Westmead Hospital, Casuarina Lodge provides short term accommodation for patients who are receiving treatment from Westmead Hospital, Westmead Children's Hospital or Westmead Private Hospital, and their families.
- Patients **must** have a confirmed booking for treatment before requesting accommodation at the Lodge.

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[33] What this fee is not disclosed.

[34] Factors not listed

[35] Except for breastfed babies.

[36] Cost not listed

[37] https://www.wslhd.health.nsw.gov.au/Westmead-Hospital/Patient-Visitor-Information/Accommodation-for-Westmead-Hospital-Visitors/Westmead-Hospital-overnight-rooms

[38] Information from Casuarina Lodge page Westmead hospital - https://www.wslhd.health.nsw.gov.au/Westmead-Hospital/Patient-Visitor-Information/Accommodation-for-Westmead-Hospital-Visitors/Casuarina-Lodge

- Priority is given to cancer patients and their families but other families can be accommodated if there are rooms available.

Cost

- $43.00 per night for one adult
- $60.00 per night for two adults

Chisholm Cottage[39]

Chisholm Cottage is only available to those from outside the Sydney metropolitan area travelling to Sydney for personal or family medical reasons. While we warmly welcome adults without children, we do not allow more than two adults per room. Chisholm Cottage is a smoke and alcohol-free environment.

Cost

- $60 per night - Double room or twin room (max 2 guests)
- $80.00 per night – Family rooms (max 4 guests)

The Leukaemia Foundation Patient & Family Accommodation Complex[40]

They have a few apartments in Sydney one near Westmead made for long stay blood cancer patient accommodation.

The accommodation is subsidised or free when possible.

The Northmead Unit[41]

The National Cancer Foundation is an independent charity devoted to reducing cancer in the community, while working to assist people already affected by cancer. Priority is given to cancer patients attending Westmead Hospital or Westmead Children's Hospital and their families.

Fees not listed.

Wesley Apartments[42]

Wesley Apartments provide accommodation to patients at Westmead Hospital and also to the families of children who are undergoing treatment at The Children's Hospital at Westmead.

There is a minimum stay of 21 nights (3 weeks).

Cost

- $100 per night

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[39] Information form Westmead hospital site https://www.wslhd.health.nsw.gov.au/Westmead-Hospital/Patient-Visitor-Information/Accommodation-for-Westmead-Hospital-Visitors/Chisholm-Cottage

[40] https://www.leukaemia.org.au/our-services/accommodation-services/nsw-accommodation/

[41] https://www.wslhd.health.nsw.gov.au/westmead-hospital/patient-visitor-information/accommodation-for-westmead-hospital-visitors/the-northmead-unit

[42] https://www.wslhd.health.nsw.gov.au/westmead-hospital/patient-visitor-information/accommodation-for-westmead-hospital-visitors/Wesley-Apartments

- $500 Security deposit (refunded on satisfactory inspection)
- $180 Exit Clean (Payable on departure)

Local hotels and Motels

175 One Hotels and Apartments - Starting at $125-178 per night[43]
Absolute Waterfront Apartments, Westmead - Starting at $79 – 135 per night[44]
IBIS Budget, Wentworthville - Starting at $74-103 per night[45]
UWS Village[46] – Prices not listed for short stays

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[43] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[44] From Waterfront Apartments Website, https://waterfront-apartments.com.au/furnished-properties?suburb=westmead

[45] Costs for one night over the Dec-Jan period min-max starting prices, collated by Google

[46] https://www.wslhd.health.nsw.gov.au/Westmead-Hospital/Patient-Visitor-Information/Accommodation-for-Westmead-Hospital-Visitors/UWS-Village

Telehealth

World Health Organization of Telemedicine:

> *"The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities"*[47]

Department of Health uses the term Telehealth as defined by the International Organisation for Standardisation (IOS) 'use of telecommunication techniques for the purpose of providing telemedicine, medical education, and health education over a distance[48]'

There is some level of Medicare funded telehealth support however coverage in Canberra is patchy[49] depending on service and it would make sense to have a more structured program that is aimed to provide linkages between the Canberra Hospitals and Remote Specialists.

Telehealth seems to be being used by the Southern NSW Local Health district to help reduce travel costs, improve access to health and support services and improving patient safety by keeping them off the road[50]. Currently Tuberculosis support seems to be the major publicly visible telehealth service[51]

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[47] WHO. *A health telematics policy in support of WHO's Health-For-All strategy for global health development: report of the WHO group consultation on health telematics, 11–16 December, Geneva, 1997.* (Geneva, World Health Organization, 1998) as quoted in *Telemedicine: opportunities and developments in Member States: report on the second global survey on eHealth 2009*, World Health Organization 2010

[48] IOS as quoted by the Department of health https://www1.health.gov.au/internet/main/publishing.nsf/Content/e-health-telehealth

[49] You can see this on the map https://beta.health.gov.au/resources/apps-and-tools/health-workforce-locator?utm_source=doctorconnect.gov.au&utm_medium=redirect&utm_campaign=digital_transformation&utm_content=%2Finternet%2Fotd%2Fpublishing.nsf%2FContent%2Flocator

[50] https://www.snswlhd.health.nsw.gov.au/our-services/telehealth

[51] https://www.snswlhd.health.nsw.gov.au/our-services/telehealth/available-telehealth-services

Financial Aid Options

Carer Allowance[52]

A fortnightly supplement if a person gives additional daily care to someone who has a disability, serious illness, or is frail aged.

Eligibility

If the person is providing additional daily care and attention to someone because of a disability, a severe illness or they are frail aged and is likely to be doing so for at least 12 months. The person receiving care must be:

- 16 or older; or
- A child younger than 16 and the parent/guardian does not receive the Carer Payment for them.

Both the carer and person receiving care must be:

- Australian residents
- in Australia[53].

To be eligible the parents/partners combined adjusted taxable income must be under $250,000 a year.

If the child or children are younger than 16 years of age:

The child getting care must meet all of the following:

- Have a recognised disability or score high enough on the Disability Care Load Assessment (Child) Determination 2010 (DCLAD);
- Be likely to have the illness or disability for at least 12 months, unless it's terminal[54];
- Need care from the carer in their home or in hospital.

Or if the person provides care for 2 children under 16 if:

- Their care needs add up to the same care as for 1 eligible child;
- The carer and the health professional who treat each child getting care must answer questions for the DCLAD.

If the child or children are older than 16 years of age:

The child receiving care must:

- Score high enough on the Adult Disability Assessment Determination 2018 (ADAT);

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[52] Information gathered from https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance

[53] It is unclear how this payment is affected by recreational/respite/treatment overseas travel e.g. Cancer kids going to Disneyland etc. From the reading it appears that the payments will stop while they are traveling.

[54] We need to talk more broadly about the use of the term terminal for children, use the term life-limiting is more cognisant of the importance of hope for family's emotional resilience.

- Be likely to have the illness or disability for at least 12 months, unless it's terminal[55];
- Get care from the carer in their home, the carer's home or in hospital.

Amount

I the case of shared care situations where the other parent is not the person claiming's partner. Each person gets part of the payment depending on how much care they each provide.

Caring for a child over 16:

Carer allowance is $129.80 each fortnight and does not provide a health care cared for the person receiving care.

Caring for a child under 16:

- For a child with high needs the carer allowance is $129.80 each fortnight and a health care card for the child.
- For a child with low needs there is no fortnightly financial amount but the child does get a health care card.

Carer Adjustment Payment[56]

A one-off payment if the parent/guardian's child under 7 gets a severe illness or has a major disability. With a maximum amount of up to $10,000 tax free, depending on the family's circumstances.

Eligibility

The child must have either a:

- Severe illness;
- Severe medical condition; or
- Major disability.

They must also meet the following rules:

- They must get Carer Allowance for the child;
- They must have a very strong need for financial help;
- The child must need this care for at least 2 months;
- The child must have the severe illness, medical condition or major disability because of a catastrophic event[57]; and
- The carer or partner can't be getting Carer Payment or be able to get another income support payment from us.
- It must be less than 2 years after the first time a doctor diagnoses the severe illness, medical condition or major disability.

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[55] See note above on the use of the term terminal regarding children.

[56] Information gathered form https://www.humanservices.gov.au/individuals/services/centrelink/carer-adjustment-payment

[57] Catastrophic events are defined as things like: a car accident; a childhood stroke; childhood cancer; a fall; a fire; a poisoning; near drowning.

Carer Payment[58]

Income support payment if a person gives additional daily care to someone who has a disability, serious illness, or is frail aged.

Eligibility

To get this the carer must:

- Be under the pension income and assets test limits;
- Be an Australian resident;
- Both must be usually in Australia;
- Care for someone who is an Australian resident;
- Care for 1 or more people who have care need scores high enough on the assessment tools used for an adult or child; and
- Care for someone who'll have these needs for at least 6 months or the rest of their life.

If the person that is being cared for doesn't get a pension or benefit from us or the Department of Veterans' Affairs, both their:

- Income must be less than $114,359 a year; and
- Assets must be worth less than $705,500.

In the case of a child under 16 the income and assets assessment combines the total income and assets of the child, their parents and parents other dependent children. Each of them must either earn less than the income test or own less than the assets test.

If the child or children are younger than 16 years of age:

The child getting care must meet all of the following:

- Have a recognised disability or score high enough on the Disability Care Load Assessment (Child) Determination 2010 (DCLAD);
- Be likely to have the illness or disability for at least 6 months or a terminal illness[59];
- Need care from the carer in their home or in hospital.

Even if the person getting care has lower care needs they may pay Carer Payment for either:

- 2 to 4 children under 16 whose needs add up to the same as 1 child with severe needs
- 1 or 2 children under 16 and 1 adult whose needs total the same as 1 child with severe needs.

They also pay Carer Payment for a child under 16 who needs either:

- A lot of care for a short time i.e. A **short-term condition** is likely to be a one off and last for at least 3 months; or
- Care on an episodic basis for 3 to 6 months i.e. An **episodic condition** is likely to happen from time to time.

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[58] Information from https://www.humanservices.gov.au/individuals/services/centrelink/carer-payment

[59] We need to talk more broadly about the use of the term terminal for children, use the term life-limiting is more cognisant of the importance of hope for family's emotional resilience.

If the child or children are older than 16 years of age:

The child receiving care must:

- Score high enough on the Adult Disability Assessment Determination 2018 (ADAT);
- Be likely to have the illness or disability for at least 12 months, unless it's terminal[60];
- Get care from the carer in their home, the carer's home or in hospital.

Amount

Pension rates per fortnight	Single	Couple each	Couple combined	Couple each separated due to ill health
Maximum basic rate	$850.40	$641.00	$1,282.00	$850.40
Maximum Pension Supplement	$68.90	$51.90	$103.80	$68.90
Energy Supplement	$14.10	$10.60	$21.20	$14.10
TOTAL	$933.40	$703.50	$1,407.00	$933.40

Community Financial Support Services

Rise Above - Capital Region Cancer Relief (Previously the ACT Eden Monaro Cancer Support Group)[61]

They provide financial support to cancer patents in Canberra, Queanbeyan and surrounds (any type of cancer). They help with the many of the costs associated with cancer such as medication relating to current treatment for cancer, chemotherapy, food supplements and food & petrol vouchers and electricity accounts.

Stella Bella Little Stars Foundation

Stella Bella assists families who are struggling financially, whilst caring for a seriously ill child. They provide food and petrol vouchers, pay for chemist accounts, emergency accommodation and other more tailored assistance as required.

Stella Bella also provides bereavement support, providing financial grants and memorial jewellery for families on the sad occasion of the loss of a child. They also actively support families who are caring for a child in palliative care, in any way they can, to help the families spend as much time as they can with their precious child.

Camp Quality

Camp Quality's Financial Support Program provides help for bereaved families in extreme financial difficulty.

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[60] See note above on the use of the term terminal regarding children.

[61] https://riseabovecbr.org.au/rise-above-cancer-convoy/how-we-help/

NDIS Notes

Parents noted that when a child goes from an NDIS Long term condition to palliative care that their payments are no longer available, hence some parent's reticence to access palliative services or acknowledge that their child is at a palliative stage in their care. It appears that the NDIS should still provide the support for the child for those things that are specifically related to the disability. It does appear that any acute conditions related to the original condition may not be covered e.g. rehabilitation from surgery required by an issue created by the original condition. However if home modifications are required for the patient to return home after the surgery those should be covered.

"Health supports that will NOT be provided by the NDIS
Health-related services and supports that **will not** be provided or funded through the NDIS include:

- Items and services provided as part of diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions, and which are not part of the everyday life of the NDIS participant
- Medically prescribed care, treatment or surgery for an acute illness or injury including post-acute care, convalescent care and rehabilitation
- Sub-acute care including palliative care, end of life care and geriatric care (with the exception of supports that are already provided for in a participant's plan – refer **Palliative Care**)
- Items and services covered by the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS)
- Treatment, services or supports delivered by a doctor or medical specialist, including diagnosis and assessment of a health condition."[62]

"Does the NDIS provide supports for participants who have a palliative care plan in place?
Where a NDIS participant has a palliative care plan in place and is not hospitalised, the NDIS will fund supports required as a direct result of the disability where the support assists the participant to undertake activities of daily living. These supports may be provided at the same time as palliative care supports[63].

The NDIS is, however, not responsible for palliative care. As set out in Council of Australian Governments' agreed *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* (including the Applied Principles and Tables of Support (APTOS)), palliative care is provided by the health system.[64]"

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[62] From *"How the National Disability Insurance Scheme (NDIS) and health services will work together"* https://www.dss.gov.au/sites/default/files/documents/06_2019/attachment-drc-communique-fact-sheet-health-related-supports.pdf

[63] This clarification looks like it was put into effect October 2019. Prior to that it appears that they may have stopped supports if the individual was declared palliative, however it is not clear.

[64] From *"How the National Disability Insurance Scheme (NDIS) and health services will work together"* https://www.dss.gov.au/sites/default/files/documents/06_2019/attachment-drc-communique-fact-sheet-health-related-supports.pdf

"The NDIS funds:

- Allied health and other therapy needed because of a person's disability, including occupational therapy, speech therapy or physiotherapy.
- Personal care to assist with day to day care needed because of a person's disability and development of skills to help a person become more independent.
- Training of carers and informal supports to implement health care plans developed by health professionals.
- Prosthetics and artificial limbs (surgery remains the responsibility of the health system).
- Aids and equipment such as wheelchairs, adjustable beds or hearing aids related to a person's disability.
- Therapeutic and behavioural supports.
- Home modifications needed because of a person's disability, to enable discharge from a hospital.[65]"

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[65] From https://www.ndis.gov.au/understanding/ndis-and-other-government-services/health

Canteen[66]

Provides support and assistance for young people (12-25) who have been diagnosed or have a parent or sibling with cancer.

Canteen provides information for teens who are diagnosed with cancer or have a sibling, parent or friend who have been diagnosed with cancer.

Canteen provides, resources, counselling, camps and other social activities. To register for the supports you can register online, via e-mail or phone call.

Youth Cancer Services[67]

Eligibility

Youth Cancer Services provide specialist and age-appropriate treatment and support for young cancer patients aged 15-25. The patient needs to be referred to the service by a qualified Health professional.

Services

Youth Cancer Services provide young patients with:

- specialist care by an expert team of medical and allied health professionals with experience in treating cancer in young people
- treatment that is planned and managed by a multidisciplinary team
- a designated Cancer Care Coordinator– a nursing or allied health consultant who will be their personal guide through the often-confusing health system
- psychosocial care to meet the unique needs of young people, including help coping with cancer and side effects, and help returning to your family, community, school and/or work after treatment ends
- access to fertility preservation information and options
- improved access to new clinical trials and research
- respect – treatment and support that recognises and values individual diversity
- youth-friendly environments – with other patients of similar age and age-appropriate facilities.

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[66] Information gathered from https://www.canteen.org.au

[67] Information gathered from https://www.canteen.org.au/youth-cancer/

Camp Quality[68]

Camp quality offers services and programs services made specifically to help kids aged 0-13 who are dealing with their own diagnosis, or the diagnosis of someone they love, like a brother, sister, mum or dad.

They provide a range of services that can be accessed at different times and locations.

When at home

- Our Kids Guide to Cancer App – supports kids who have a parent, sibling, friend or loved one with cancer
- The New Normal Navigator App – online tool designed to give parents of kids diagnosed with cancer the resources to help adjust.
- Financial Support Program – to help bereaved families in extreme financial difficulties

When at Hospital

- Child Life Therapists – help kids deal with being in hospital by teaching them playful ways to understand medical procedure and coping skills to help reduce anxiety.
- In Hospital Support
    - Camp Quality Puppets – Visit kids in hospital each week, to help ease anxiety and make them laugh.
    - Family Liaison Co-ordinators – visit kids every week overing support, advice and the essential connections families need to both Camp Quality's services and others.
- Beads of Courage – a program at Sydney Children's hospital Randwick, that is used to track each hospital procedure.

When at School

The Primary School Education Programs, the camp quality puppets visit primary and pre-schools across Australia that work to create a fun and educating program that helps to dispel the myths around cancer and creates and inclusive community for children who have been diagnosed with, or who have a parent or siblings with cancer.

The program has information and resources for Parents, Kids and Teachers to help provide a full and educational experience.

Away from Home

- Kids Camps – provides kids dealing with cancer the opportunity to get away from it all.
- Family Camps – are an opportunity for parents, children and siblings to reconnect with each other and make new connections with other families in a similar situation.

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[68] Information gathered from https://www.campquality.org.au

- Family Fun Days – give families the chance to get together and enjoy something that may not otherwise have the opportunity to do e.g. surf school, whale watching, a day at the farm.
- Family Experiences – free tickets to the zoo, football or shows
- Retreats – holidays locations designed for families in remission, post-treatment or in bereavement. Located in Coffs Harbour and Salamander Bay (NSW), Warrnambool (VIC) and West Beach Caravan Park (SA).

National Palliative Care Standards

“**Children with a life-limiting conditions**

Caring for infants (including the perinatal period), children and adolescents (referred to as child or children) with a life-limiting condition can have unique characteristics that differentiate it from the provision of care for adults. The needs of the child, and their family, vary considerably based on their developmental stage and the range of conditions seen can lead to a variety of illness trajectories that can make predicting a prognosis difficult. The way in which children process information, the methods for assessing and managing their pain and other symptoms and their ability and willingness to participate in decision making all needs to be considered. Children may remain under the care of their primary treating team, receiving care aimed at a cure in parallel with support from specialist paediatric palliative care through a consultative model.[69] Paediatric palliative care embraces the physical, emotional, social and spiritual elements from the point of diagnosis or recognition through to death and beyond. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.[70]"

“**Palliative Care Australia defines paediatric palliative care as follows:**

Palliative care for children with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition,[71] embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.[72]”

“PCA and PaPCANZ support that children may receive palliative care alongside medical treatment aimed at a cure, and can be integrated at any point in the illness trajectory. Some children receive palliative care for a short time, while others are supported for many years. Children differ from adults in many ways and the needs of a child vary considerably based on developmental stage, from perinatal through to adolescence. Predicting prognosis and when they may die can be difficult.[73]”

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[69] IMPORTANT – the parent can still pursue curative treatment and receive palliative support.

[70] From the *“National Palliative Care Standards 5th Edition 2018”*, Palliative Care Australia

[71] This is important to note paediatric palliative care is from the point of diagnosis.

[72] From *“Paediatric Addendum: Palliative Care Service Development Guidelines”*, 2018, Palliative Care Australia

[73] From the *Policy Statement: Paediatric Palliative Care* a joint policy statement from Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ)

Clare Holland House[74]

Clare Holland House (CHH) is the primary palliative care facility in Canberra. It provides a range of palliative services for patient as an inpatient service, at home or in residential facilities.

Their community specialist palliative care services aim to:

- Advise and support the primary care team
- Manage distressing symptoms
- Offer home visits if necessary
- Facilitate access to equipment to support the patient to stay in the home setting as long as possible.
- Provide telephone advice
- Provide inpatient care at the ACT Hospice
- Teach the family how to care for the patient
- Support the bereaved

Patients can be admitted for pain and symptom management, respite care or terminal care. This service is primarily an adult facility however it does support children when required.

The inpatient care admission form seems to imply that the inpatient services are primarily for end-of-life care. It also requires the referring medical professional to specify the expected life expectancy, under the National palliative care standards (previous section) it is noted that in the case of paediatric palliative care that life expectancy is particularly hard to determine.

Their community-based admission form seems to be more open to the breadth of life-limiting conditions that exist in a paediatric context.

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[74] Information primarily gathered from https://www.calvarycare.org.au/public-hospital-bruce/services-and-clinics/clare-holland-house/

Other Miscellaneous Resources

Long Term Follow up nurse

Long Term Follow up nurse for Oncology Sydney Children's Hospital, 5 years post treatment get referred here for health monitoring and education. It allows them to keep an eye on the possible long-term side effects of paediatric cancer treatments.

https://www.schn.health.nsw.gov.au/fact-sheets/oncology-long-term-follow-up-clinic-information-for-patients-and-families

Sydney Children's Kids Cancer Centre (KCC) Outreach Program[lxxv]

The program is staffed by a number of outreach nurses who provide support and education to regional and rural patients, communities and hospitals. The nursing team provide all the children, adolescents and their families with support and practical assistance. They work closely with the medical team at the Hospital, local teams and the GP involved in the patient's care.

The Outreach Program covers all of NSW and the ACT, with much of the team's time spent in the larger population centres such as Canberra, Campbelltown, Wollongong, Wagga Wagga, Coffs Harbour and Port Macquarie. Whilst in these areas the nurses liaise with paediatricians, GPs, community and palliative care services as well as conducting school visits or home visits, depending on the patient's needs.

Telepresence robots in schools

ACT launched Australia wide pilot program on telepresence in schools. The Missing School program has a lot of good information on the effects of keeping kids connected as much as possible during times of illness. https://www.missingschool.org.au/page/80/telepresence

More info on the WA support for telepresence in schools: https://ddwa.org.au/robots-2019/

See article '**Robots keep sick kids in touch**':
https://www.actparents.org.au/index.php/news1/item/329-robots-keep-sick-kids-in-touch

See article '**Telepresence robot helps terminally ill Canberra schoolgirl return to classroom**'
Pictures below from above article: https://www.abc.net.au/news/2017-11-21/robo-classroom-helping-educate-seriously-ill-canberra-girl/9176204

[lxxv] Information from http://www.kidscancercentre.com/what-we-do/programs/outreach-program.aspx

Good Community Resources

'There's no such thing as a silly question: a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition' By InterACT there is a Victorian, South Australian and Western Australia Version. It might be good to look at an ACT version. It is a useful resource that covers what is available in the local area and what to expect.

Newborn & Parent Support Service (NAPSS)[lxxvi]

NAPSS provides a discharge program for the Neonatal Intensive Care Unit (NICU)/Special Care Nursery (SCN).

NAPSS provides a support service for the families of infants who no longer require intensive medical and nursing treatment but still require some nursing care, support and advice at home.

NAPSS provides six days per week (Monday to Saturday) community based or home visiting service and a 24-hour telephone support service. NAPSS assists parents in the management of the infant who maybe preterm, of small birth weight, requiring home oxygen, or require some naso-gastric feeds.

[lxxvi] Information from the NAPSS Newborn and Parent Support Service, Centenary Hospital for Women and Children Flyer

Before an infant leaves the NICU or SCN we arrange an in-patient visit to assess the infant's needs and assist the parents with the preparation for their infant's discharge home. Follow-up visits are tailored to the infant's and the parent's needs. We assess the infant's growth, assist with any feeding difficulties and offer general parenting advice.

DAISY (Directory of Assistance and Information Services for You at End of Life)

Listed Palliative care support services that include Children

- Stella Bella Little Stars Foundation – see section earlier in document
- Canteen – see section earlier in document
- Camp Quality – see section earlier in document
- Clare Holland House – Palliative care can be provided; however, the parents must acknowledge that their child is dying and the services are predominantly set up for end-of-life care.

Not Listed: Bear Cottage.

Listed Respite care support services that include Children

No specific children's support services listed. We know that Stella Bella Little Stars Foundation and Bear House provide Respite, also Clare Holland House can provide respite under certain conditions.

Listed Services for Grief support and counselling

- Canberra Grief Centre
  The Canberra Grief centre can support a person after a loss, during the process of losing such as that experienced by carers, where diagnosis has been received or at end of life. It says that it can provide counselling to adults, adolescents, children, individuals, couples and families.
- The Compassionate Friends of ACT and Queanbeyan
  The Compassionate Friends of ACT and Queanbeyan is part of The Compassionate Friends (TCF) world-wide network. It offers support in managing the trauma and grief that follow the death of a child. They hold a monthly meeting at the Grant Cameron Community Centre, 27 Mulley St, Holder, on the first Tuesday of the month at 7 pm.
- Guiding Light
  Provides support to parents after the death of a child. It looks like parents or families are usually referred to the service by health professionals, however it also looks like they may be able to reach out to the service directly though it is not clear. Their services include counselling, parent and family support, peer support, sibling support, grandparent support groups, group activities, annual memorial services, telephone counselling and a national 24-hour free call 1300 308 307 bereavement support line. Services are available to families and their support network free of charge.
- Kids Helpline
  Provides a 24/7 phone and online counselling service for young people aged 5 to 25.
- Sands

Sands is a volunteer-based organisation that provides support for miscarriages, still births and newborn deaths.

- Good Grief
  Provides adult and child programs, however it is not clear when & where these programs are run. From the information on their website it seems more like an information hub rather than a grief specific service.
- ACT Health Cancer Counselling
  Only available for people 16+
- ReachOut.com
  ReachOut.com is Australia's an online mental health organisation for young people and their parents. It seems to be predominantly an information service. However, they do have some urgent help links.

The Back on Track Program

The Back on Track program enables children undergoing long-term cancer treatment to continue with their education, with the support of a dedicated teacher funded thanks to the Fight Cancer Foundation.

This service is available at the Royal Children's Hospital Melbourne, The Children's Hospital at Westmead, Sydney and Children's Hospital at Randwick and the Women's and children's Hospital in Adelaide.