Improving Palliative Care for Teenagers and Young Adults

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2023 Churchill Fellow

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Glossary

ACP	Advanced care plan
AYA	Adolescents and young adults
CYP	Children and young people
CYPACP	Children's and young person's advanced care plan
HLH	Haemophagocytic lymphohistiocytosis
MAID	Medical Assistance in Dying
MDT	Multi-disciplinary Team
PALSIG	A national special interest group of healthcare professionals for palliative and end-of-life care for teenagers and young adults
PEOLC	Palliative and end-of-life care
PESST	Physical, emotional, social, spiritual and trajectory
PMOST	Paediatric Medical Order for Support at the End of Life
QCH	Queensland Children's Hospital
RFH	Rotary Flames House
SCH	Sydney Children's Hospital
TYA	Teenage and young adult
VMC	Voicing My Choices

Executive Summary

Background

Teenage and young adult (TYA) palliative care is an area of cancer care with great potential to improve quality of life for a group of patients who, at a critical time in development, receive the most devastating diagnosis which profoundly disrupts all aspects of their life and takes away their future. As clinicians we are often most focused on medical treatment and achieving a cure and, once it becomes clear that this is not going to be possible, it can be difficult to introduce the concept of palliative and reframe the focus of care to quality of life. It is essential that as healthcare professionals we hear the voices of our patients and understand their preferences and opinions about their wishes for the remainder of their life and their end-of-life care. The focus of this project was to understand what international teams can teach us about communication and documentation of patients' wishes around palliative and end-of-life care, and the education of healthcare professionals on this subject. My Churchill Fellowship involved 8 weeks of research abroad working with palliative care teams in Sydney and Brisbane in Australia (March-April 2024) and Vancouver and Calgary in Canada (July 2024).

Findings

During the first phase of research in Australia, I learnt about the multi-stage, patient-centred, development of the advanced care planning document 'Voicing My Choices Australia', which was co-designed with teenagers and young adults. I experienced first-hand how it was implemented with patients, how it is integrated into their medical advanced care planning (ACP) document and the ongoing multi-centre research into its efficacy and acceptability in improving palliative care for TYAs. During the second phase of research in Canada, I learnt about their work developing and utilising the PESST model for discussions about palliative care, and the development of the paediatric serious-illness conversation guide and online education programme for healthcare professionals to support this.

Recommendations

This research gave me wide-reaching insight into the potential resources available to improve our communication and documentation of TYA patients' wishes about their palliative and end-of-life care in the UK. Sharing my findings with the wider community of healthcare professionals in the UK would allow us all to learn from my experience and together explore new avenues of communication to improve our understanding of the wishes and needs of TYA patients and therefore provide more patient-centred and holistic palliative care. My recommendations for the future of palliative care in the UK involve developing a UK version of 'Voicing My Choices' to improve our communication and documentation of the wishes of terminally ill young people, and developing an education programme for healthcare professionals to improve our capabilities at holding these discussions.

Background

My journey to undertaking a Churchill Fellowship began in January 2022 when I started a new role as a Paediatric Trainee Doctor on the Paediatric Haematology and Oncology Team at Oxford University Hospitals. Oxford is a tertiary regional centre for paediatric patients with cancer (Leukaemia, Lymphoma and Solid Tumours) and is the principal treatment centre for patients all across the region, covering an area that includes Oxfordshire and parts of Buckinghamshire, Berkshire and Wiltshire. The majority of treatment is delivered from Kamran's Ward and Kamran's Day Care in the Children's Hospital at Oxford University Hospitals.

The Children's Hospital, Oxford University Hospitals

During my time there, I looked after a number of TYA (teenage and young adult) patients undergoing palliative care following unsuccessful treatment for cancer. There were two cases in particular that really stuck with me and inspired me to want to improve the way we provide palliative care to this patient group. The first case was a 16-year-old boy who presented with a relapsed sarcoma having only completed treatment and been in remission for less than 6 months. His cancer progressed quite quickly despite chemotherapy, which had been initially with curative intent and his condition soon became palliative. Due to his previous experience with cancer treatment, he was very aware that the cancer wasn't responding as we had hoped and when it became clear that he wasn't going to survive, he began thinking about what he wanted to do with the time he had remaining and communicating this to his family and the members of the team he felt the best connection with. The members of the team he felt best able to talk to were the community nursing team, who he had built a rapport with during his previous treatment. He also began to share with them his thoughts and worries about death and dying. They understood why he felt able to share it with them and took the time to talk to him, but felt that they weren't adequately trained and didn't have the education or tools to manage such conversations, and as a result felt out of their depth in this area. One of his main wishes was to travel to Scotland, where he had family, and see the mountains one last time. As a team we tried to help plan for this, but due to the burden of chemotherapy and the rapid progression of his tumour, the trip was delayed, and ultimately didn't happen.

The second case was a 12-year-old girl, who was a new presentation of a femoral osteosarcoma. She was started on the usual chemotherapy protocol but the tumour was aggressive and failed to respond to treatment. It became clear, very early on, that cure was going to be unlikely. She was very bright and perceptive, and although no one had told her that her condition was likely palliative (at her parents' request), she asked questions and spoke to the team in such a way that it was clear that she understood. Her most common question and request was about returning to school, but as her parents wanted to pursue full active treatment, she was unable to do this, due to being an inpatient for surgery and chemotherapy right up until she passed away.

Both these cases made me reflect on what we could have done to improve care for these patients. I felt that both of these patients were clear and outspoken about what they wanted but we (both the medical team and potentially also their families as well) didn't hear what they were saying, and as a result, they both missed out on opportunities that would have brought them joy before they passed away. I also felt that if we couldn't hear the voices of these patients who were speaking to us loudly and clearly, then we are definitely missing out on hearing the voices of the patients who are less confident and less able to express their thoughts. After all, it must be intimidating to speak out to a room full of doctors, nurses and your family.

Aims and Objectives: Initial Research

This led me to look for ways that I could try to change things for future patients like these. Not long after I looked after these patients, in summer 2022, PALSIG (a national special interest group for TYA palliative and end-of-life care (PEOLC)) was being set up and I became one of the first members of this group.

This group was formed of like-minded individuals across the whole UK working with teenagers and young adults with a palliative diagnosis with the sole goal of improving and tailoring the care we provide them. Joining this group allowed me to connect with like-minded professionals, many of whom have much more experience than me in this area. It also allowed me to develop my ideas about ways in which we could improve the care for these patients. My main ideas, which have formed the aims of my Churchill Fellowship are to explore:

1. Improving advanced care planning for teenagers and young adults, including developing a written tool for this purpose.

2. Improving the education of healthcare professionals in communication around palliative and end-of-life care for teenagers and young adults.

I joined the task and finish group (a subgroup of the special interest group) focused on the education of healthcare professionals, and ran a pilot scheme for providing teaching to Paediatric Trainee Doctors on PEOLC for TYAs from February to August 2023. I designed this pilot scheme by approaching deaneries offering paediatric speciality training across the UK, making contact with the teaching coordinators for each region and offering them a 1-hour teaching session on TYA palliative care, to coincide with their trainees' monthly mandatory teaching days. Most of the deaneries that responded were keen to include this teaching in their programme, apart from those denaeries that were already delivering teaching on this topic. The pilot scheme delivered 7 teaching sessions, given by 3 different speakers to paediatric trainee doctors across the UK. Regions covered included: Southeast Scotland, South Wales, North East, Thames Valley (Oxford), East Midlands, South West. I estimate that up to 100 paediatric trainees were reached by these teaching sessions. I sent out a brief feedback form for each of the teaching sessions, an example of which can be found in Appendix 1. I received 11 responses and the feedback was overwhelmingly positive.

Before the teaching session, the average participant rated their confidence in caring for teenagers and young adults with palliative diagnoses as 4.8/10 (where 1 was 'not confident at all' and 10 was 'very confident'). After the teaching session, the average participant rated their confidence as 7.1/10.

When asked which parts of the teaching were most useful and why, responses included:

'I think the case example highlighted the challenges of looking after patients in transition really well.'

'Useful to hear about different cases and logistics of service provision. Good highlighting of using your teams available.'

'Transition from children to adult palliative care medicine.'

'Discussion of advocating for CYP with palliative diagnoses, particularly those in transitioning phases or living in more remote areas.'

'Discussions about obstacles to good care and how to overcome them.'

'When to start discussion with teenagers and how soon.'

'The explanation of how the palliative care team works and the kind of patients they see and are involved with. Really helps to also get a better idea of how many patients and with what diagnoses are the ones mostly in need and what kind of input you might have. Palliative care is very much on the periphery I feel within paediatrics whilst in adult medicine it is pretty much an everyday topic, so I feel a bit out of touch having now worked in paeds for a while, but it is really useful to be reminded that even paediatric patients may still require the specialty's input.'

When asked which parts of the talk were least useful, responses included:

'Geographical area specifics.'

'Area specific.'

'N/A.'

'None.'

When asked what topics they would like to see included in future sessions, responses included:

'More case histories for discussion would be great!!'

'Some teaching on symptom control and basic palliative care initial treatment.'

'Sessions on symptoms management would be useful.'

'Sign posting for families.'

'Would be helpful to include non-oncology cases and discussion of palliative support in life limiting conditions.'

'Prescribing for symptom management in paediatric palliative care (going beyond the first line medications), particularly for care out of hours.'

'PICU medications.'

'I am really interested to learn more about palliative care and am very interested in the additional course/study day that was recommended at the end of the session.'

I felt that this pilot teaching scheme was overall really successful and showed that there was both enthusiasm and the need for teaching on this topic for paediatricians within their training.

Whilst running this teaching pilot scheme, I also began researching advanced care planning tools currently available for teenagers and young adults in the UK, including gathering information about this from colleagues in the PALSIG group. One of the most commonly used documents by medical professionals for documenting the more medical aspects, including whether the patient is for resuscitation or not, is the CYPACP (Child and Young Person's Advanced Care Plan). The website for the CYPACP collaborative, which includes the documents and the guidance for their use is below and I have included a blank example copy of this form in Appendix 2.

https://cypacp.uk/

This document is extremely useful mainly for healthcare professionals to record and communicate information about the patient and their diagnosis and the plans for their medical care. However, it is not TYA specific and it is also not primarily aimed at the young person themselves, and their wishes. On 11th May 2023, Ross Smith who is the co-lead of the CYPACP collaborative, spoke to the PALSIG group about the latest version of the document. From the discussion after the talk, it was suggested that it was a useful document for healthcare professionals to record medical information and plans, but that it could be intimidating for TYAs to work through, it wasn't very user friendly for TYAs, it wasn't TYA specific and it didn't cover all the topics/information that we felt might be relevant.

Another advanced care planning tool available in the UK for adults is called 'My Wishes'. This is a free digital tool that helps adults plan for their end-of-life care and their death, as well as including options for helping them write a will, write a bucket list, leave goodbye messages, plan for their digital legacy and plan their funeral. The website for accessing this tool is here:

https://www.mywishes.co.uk/

The creator of My Wishes, James Norris, also spoke at our PALSIG group on 13th April 2023, explaining how it works and that it has been very successful with adults so far. We also discussed the possibility of designing a version specific for TYAs, and he was able to produce a quote for the PALSIG group for the initial costs required to do this. This was strongly considered at the time, but due to the high cost and time commitment (3 years), it was felt that we could not proceed.

After this research I felt that there wasn't any ACP tool currently available in the UK aimed at TYAs. However, the research showed that these patients do want to talk about their end-of-life care and that they benefit from doing so. Healthcare professionals often worry that conversations about advanced care planning and end of life will be distressing for young people; however, studies show that young people would like this opportunity (Friebert et al., 2020) and that early inclusion of palliative care for patients with cancer leads to higher-quality care at end of life (Hannon et al., 2016, Zimmerman et al., 2014). However, studies also show that this typically happens too late, and sometimes not at all (Cuviello et al., 2021). One suggested reason why these conversations with TYAs are postponed or avoided is lack of healthcare professional confidence in how to manage these conversations (Hughes et al., 2022). One study that trained healthcare professionals working with adolescents who are dying to use 'Voicing My Choices', an advanced care planning tool developed for AYAs, found that they felt more confident in holding these end-of-life conversations after this training (Smith, 2017). In the UK we refer to this patient group as TYAs (Teenagers and Young Adults); however internationally, they are called AYAs (Adolescents and Young Adults).

International Research

This led me to start researching tools that are being used overseas currently. One of the PALSIG co-chairs mentioned an interesting and exciting talk that she had been to, given by Dr Ursula Sansom-Daly, a researcher based in Sydney. Dr Sansom-Daly is a Senior Research Fellow in the School of Clinical Medicine at the University of New South Wales (UNSW) and

Director of the Behavioural Sciences Unit in the Kids Cancer Centre at Sydney Children's Hospital. One of the focuses of her research is the development of resources and interventions to improve the cancer experience for patients and co-designing advance care planning and communication support resources for AYAs whose cancer may not be curable. Dr Sansom-Daly led the development of the Australian version of 'Voicing My Choices' (VMC), which was co-designed with AYAs in Australia, and is overseeing the current research looking at its efficacy when implemented into practice for AYAs with palliative diagnoses. VMC was originally developed in the US by Dr Lori Weiner, but is felt to be too culturally American for the Australian AYAs. As a result Dr Sansom-Daly developed a version specifically for the Australian audience, and I was very interested to learn about that development process, and to review the Australian document, as both the culture and medical system in Australia seem closer to ours in the UK. To learn more about her work, I watched a recording of a recent webinar given by Dr Sansom-Daly called 'Doing Better at Difficult Discussions with Young People with Serious Illness', which can be found at the link below.

https://www.youtube.com/watch?v=rn7sqhOjoWU

I found her talk captivating and fascinating and subsequently contacted her to ask if I could spend part of my Churchill Fellowship working with her in Sydney. She replied enthusiastically and was keen to host me, and we arranged a number of Teams meetings prior to my visit, to develop a plan for my research in Sydney and to connect me with the team they are working with to evaluate 'Voicing My Choices' based in Brisbane.

Before leaving the UK, through the PALSIG group I was also able to make connections and have meetings with people across the UK who were interested in my Churchill Fellowship and willing to help with my work after the research phase. In particular I was able to connect with Anne-Sophie Darlington, a Professor of Child and Family Psychological Health within Health Sciences at the University of Southampton, who has worked closely with Dr Sansom-Daly on previous multinational projects. Dr Sansom-Daly felt she could be a helpful collaborator for me to further my project when I return to the UK.

I also met with Merry Gibbons at the Royal Surrey County Hospital, to learn about her work with the 'Young People's Life Cafe'. Young People's Life Cafe is a series of workshops with a closed group of young people with a terminal diagnosis, led by the young people and their needs. One of their workshops looks at advanced care planning and they use a tool called the 'Wills, Wishes and Whatevers' folder, which contains a variety of pages on different topics from writing a will and funeral planning to bucket lists and making memories. One way that they have found works well when approaching this idea with young people, is to start by giving them an introduction page to explain 'Wills, Wishes and Whatevers' and then a contents page which shows them all the options for pages they could read, and letting them choose only the ones they want to see. They can revisit other pages at any time, but they never have to see any particular pages if they don't want to, or it would be too upsetting for them. I felt that this was a really thoughtful way to approach an advanced care planning tool, as it allows the TYA to lead the discussion and the pace of the discussion and to talk about only the things that they feel ready to. A number of other PALSIG members were keen to learn more about my Churchill Fellowship plans, and I gave a presentation to the members in October 2023, outlining my plans and explaining the 'Voicing My Choices' document.

After the meeting, I gave the members the opportunity to feed back their initial thoughts about VMC Australia and how useful they feel it would be for TYAs in the UK. There were 3 responses to the feedback form, and overall it was felt to be a useful document (most respondents rated most sections 4 or 5/5 for usefulness). However, they suggested that many changes would need to be made before it was used in clinical practice in the UK. This was a really useful starting point from which to travel out to Australia and learn more about the process of developing and implementing a tool like this.

Findings: Australia

Part 1: Sydney

Dr Ursula Sansom-Daly, Sydney Children's Hospital

After much preparation and planning, my itinerary was finalised and on 9th March 2024, I set off on the first leg of my research abroad, starting in Sydney, Australia. The long flight is not for the faint-hearted, especially as I had brought my 1 year old son (and husband) with me, but we eventually arrived 2 days later and settled into a lovely apartment in Coogee, which is a coastal suburb of Sydney with a lovely beach and only a 20-minute walk to Sydney Children's Hospital and the University of New South Wales, Randwick campus.

Coogee Beach

My meetings began early the following morning, on 12th March 2024, when I met Dr Ursula Sansom-Daly at a lovely coffee shop, called Twenty Two Grams, right next to the hospital, a favourite of all the staff there.

Twenty Two Grams, Randwick, Sydney

We started by discussing the aim of my trip, which was mainly learning about the development of the Australian version of Voicing My Choices from its initial inception to the current day, including the ongoing research. She also offered me the opportunity to help them work on a research study that they had conducted, and were in the process of analysing and writing up the data for journal submission. This study was conducted by the AYA Cancer Global Accord End-of-Life Study Group and collected global data about what topics and methods of training in AYA palliative care would be useful for healthcare professionals, and what barriers exist to be able to undertake this training (Sansom-Daly et al., 2022).

I was very excited about this opportunity and enthusiastically agreed to help write up this study, which tied in well with my second aim, which is to improve the education and training of healthcare professionals in AYA palliative care. She suggested I come into the Kids Cancer Centre the following day so she could show me the data and the progress they had made so far.

We then spent some time discussing the difficulties with the introduction of palliative care to patients, and how the term is loaded with connotations of death and dying, and potentially needs rebranding to make it more acceptable and accessible to patients. She had heard the team referred to as the ‘Quality of Life’ Team and felt that better explains their role, allows the team to be included from diagnosis where appropriate, helps with retaining hope and helps introduction to patients who are not currently palliative.

We finished up the meeting by discussing how Voicing My Choices Australia was first developed. It was felt to be a useful tool, but culturally there were phrases that didn’t feel as appropriate to an Australian audience. For example, one of the pages of the US version is called ‘What Brings Me Joy’, and the Australian AYAs felt that this turn of phrase was unusual and preferred ‘What Makes Me Happy’. The US version also refers to their private healthcare system and that didn’t work for Australian AYAs, for whom healthcare is accessed via a different model. This led them to do a full redesign led by AYA input and to produce the Australian version they are using today.

We finished the meeting by discussing potential collaborators in the UK that she would able to connect me with after returning from my research abroad, and making plans for a meeting and introduction to her team the following day. In the meantime, she sent me some articles to read to help me get started with the write-up of the research study. It was an interesting and fruitful start to my research abroad! I then spent the afternoon between reading up for the following day and enjoying the beach with my family.

The following day (13th March) was an early start but I had amazing views of the beach with my morning coffee:

View Down to Coogee Beach

It was my first day in Sydney Children's Hospital and I came in to work in the team office for the first time, in the Kids Cancer Centre. The day started with a tour of the hospital and especially the Kids Cancer Centre research area and introduction to other staff members on the team. I was surprised to see that the main wing of the hospital is called the Ainsworth Wing (no relation, unfortunately!).

Sydney Children's Hospital Pass

Sydney Children's Hospital Exterior

I really enjoyed the tour of the hospital, and I was most impressed by how much of a vibrant, colourful, bright place it was, and particularly how much artwork there was.

Sydney Children's Hospital Artwork

I spent the rest of the day working on the research paper, including reading the most recent draft, reviewing the literature and reading articles about palliative care training, and making notes about additions to the paper.

Later that afternoon, I met my family and went into Sydney city centre to see the Sydney Harbour Bridge and the Sydney Opera House.

Sydney Opera House

Sydney Harbour Bridge

The following day (14th March), I was back in the hospital for an 8am meeting with Dr Sansom-Daly, her colleague Donna Drew, a clinical nurse consultant who specialises in the younger age AYAs (11-15) and Lori Weiner, the original developer of Voicing My Choices in the US and her colleague Sima Bedoya. The meeting was scheduled so early because it was the only time that worked with such a large time difference.

Donna discussed the original case that triggered her interest in this work, that of an 11 year old high-achieving, outgoing girl, who developed Ewing's sarcoma, relapsed twice and unfortunately passed away at age 14. Her journey through treatment was difficult and she struggled with missing school, withdrawing from her social circle, and eventually staying in her bedroom.

This case triggered Donna's interest in hearing the voices of the young teenagers more and getting insight into their world. She did a study with 11 participants aged 11-15, through narrative story-telling, getting them to identify with a character in Alice in Wonderland and using this to speak about their struggles, thoughts and feelings. She did 3 rounds of interviews (2-3 weeks after diagnosis, 5-6 months after diagnosis and 12 months after diagnosis).

Many identified with Alice (the star of the show, central character) who falls down the rabbit hole, and likened it to their experience of free-falling after diagnosis and not being sure when it will end. Some identified with the Cheshire Cat, painting on a smile but feeling like they wished they could disappear. Some identified with the White Rabbit, as they felt they were clock-watching and waiting for treatment to end. Themes included time feeling like it was progressing really fast after diagnosis and up to starting treatment and then slowing down a lot as they moved through treatment.

She then used the information from these interviews to identify themes for this age group. Surprising themes included spirituality (2 of the participants prayed every day) and one felt her religious dress protected her from some of the difficulties of chemo as no one could see that she had lost her hair. The second theme was the joy of pets due to the unconditional love that didn't change after diagnosis and treatment. Donna felt that one thing she would change from her research if she did it again would be to interview parents at the same time to get their perspective.

Donna's plan moving forward is to create a tool to use with the 11-15 age group, as she felt some of her patients would benefit from using something like VMC but they aren't allowed to use it in this age group.

Lori Weiner suggested small focus groups or interviews where they give them a page from VMC or 'This is My World' and say 'what do you think of this?' and 'what other pages do you think would be good for people your age?'. However, one concern was that VMC may be too distressing and/or too developmentally advanced and one suggestion was to start with one page initially.

This is My World is aimed at younger children with serious medical illnesses including palliative diagnoses and is a workbook that they can use to record their thoughts and feelings about different things including their stays in hospital and their medical care. A blank example can be found at the link below:

https://ccr.cancer.gov/sites/default/files/this_is_my_world_web_508.pdf

One suggestion to help recruit parents was to use it initially as a communication tool rather than an ACP that can be used to help parents get an insight into what their children are thinking, which parents are usually very keen for.

After the meeting Dr Sansom-Daly and Donna discussed next steps including to work on methodology and initial content, and to think about resources and funding.

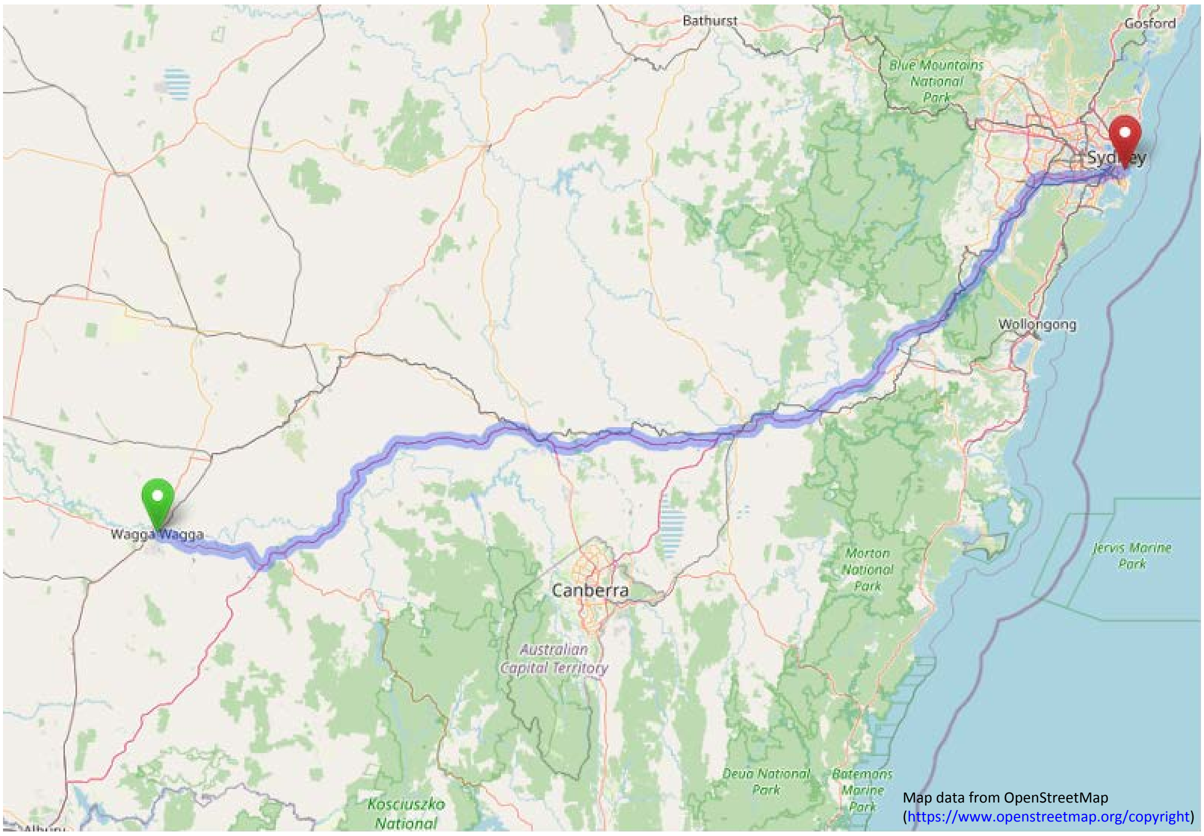
My initial thoughts on the meeting included that it was a really good insight into the initial stages of developing a communication/ACP tool e.g. brain-storming with people who have worked on similar projects and getting their thoughts on how to get started. When doing further research on 'This is My World', I found an example of the Queensland Care Plan for the Dying Child, which has a section on reviewing ACP documentation, including tick boxes for whether the child has completed My Wishes or Voicing My Choices. An example can be found at the link below:

https://www.health.qld.gov.au/__data/assets/pdf_file/0027/1429335/care-plan-dying-child.pdf

This document looks very similar to our UK CYPACP, and this could be a good way to incorporate it into our current system here in the UK. After the meeting, I discussed with Dr Sansom-Daly what my next steps would be on returning to the UK. She suggested that the easiest starting point would be to do 10-15 interviews with AYAs and get them to look through VMC Australia and give their initial thoughts and suggest changes. However, this will need ethical approval and will require significant time. She suggested I probably wouldn't be able to do and transcribe all the interviews myself, so will need help. I would therefore need a base centre for applying for ethical approval/funding and she suggested some academic connections for me in the UK.

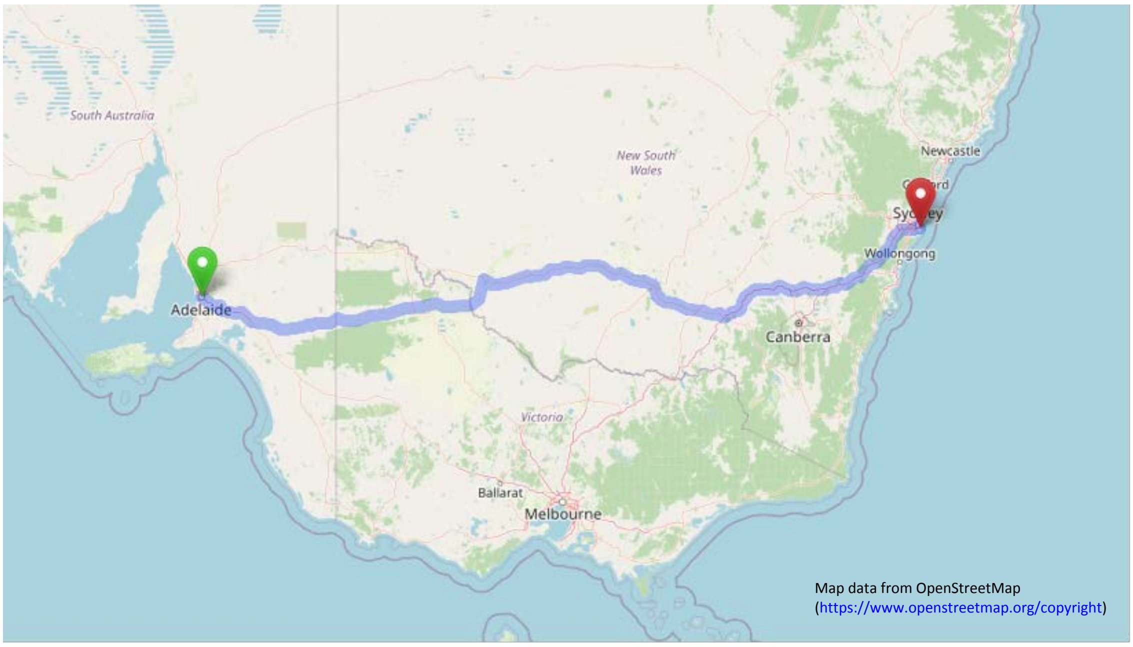
Later that day I attended the Youth Cancer Services MDT, at Sydney Children's Hospital with Dr Sansom-Daly, which involved the Consultant in Youth Cancer, social workers, psychologists and the education team. They discussed all patients who are currently in treatment and newly diagnosed patients. The meeting is led by the core group of the AYA team and they begin by discussing with the paediatric team, those in the Sydney Children's Hospital. Then the paediatric team leave and they discuss those in the adult hospital (The Prince of Wales Hospital) and for this they are joined by the adult team. I felt there was excellent coordination between the adult and paediatric teams, both in terms of systems and the individual plans for specific patients. For example, the adult team looking after an adult AYA patient was less familiar with the treatment protocol than the paediatric team, as it is a protocol commonly used in paediatrics but rarely used for adults, and the paediatric consultant offered to be on call for queries about the patient, even though they were not their primary team.

The most interesting takeaway from the meeting was the enormous geographical region covered by the Sydney hospitals. The local region that is covered by Sydney for all of the patient's treatment, is much of South/West NSW and Canberra (ACT). Current patients are from as far away as Wagga Wagga (5 hours away).

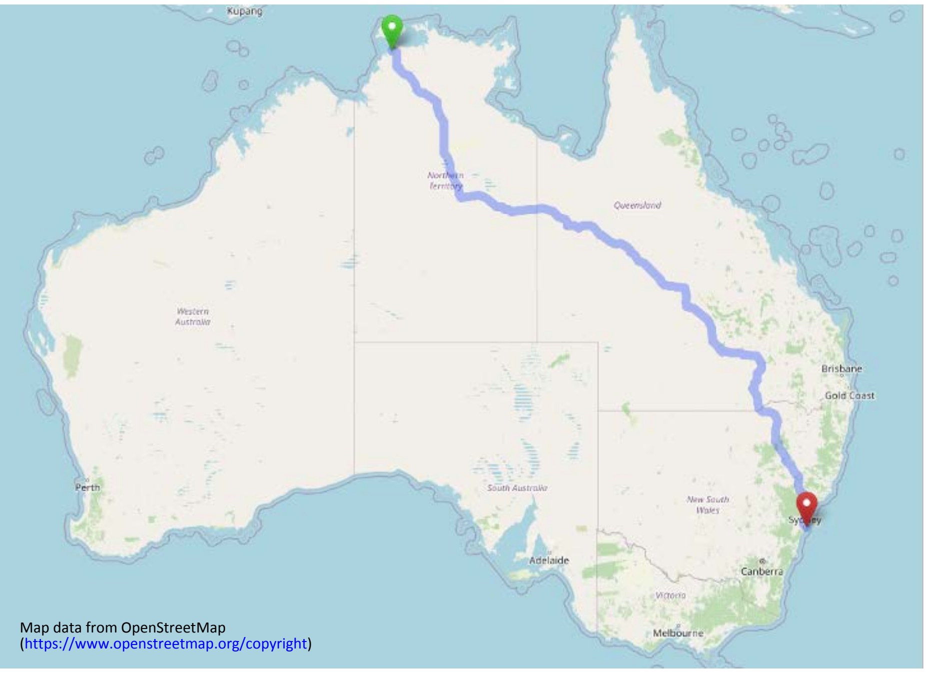


Map of the Distance between Sydney and Wagga Wagga (450 km, 5 hours 30 minutes by car)

They also transfer in from Adelaide for bone marrow transplants (patients receive the rest of their care in Adelaide). One patient was from as far away as Darwin (they would usually go to Adelaide, but they have lots of family in Sydney).



Map of the Distance between Sydney and Adelaide (1370 km, 16 hours 30 minutes by car).



Map data from OpenStreetMap (https://www.openstreetmap.org/copyright)

Map of the Distance between Sydney and Darwin (4000 km, 46 hours by car).

Because of this huge geographical region, significantly increased social care and education help is required as well as significant use of Ronald McDonald housing. There is a huge burden for parents of travel, separation from the rest of the family (e.g. siblings who are often back home) and strain on jobs. There is often anxiety from families about returning home to the care of their local centres, after they have spent significant time and developed rapport with the Sydney team.

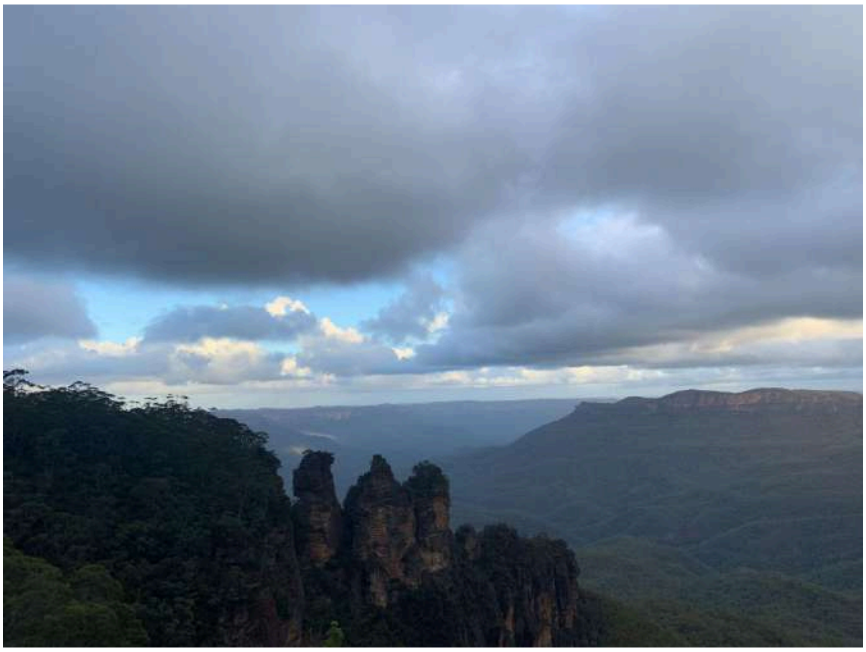
After work, I went for a relaxing walk on Bondi Beach with my family.

Bondi Beach, Sydney

The following day (15th March 2024), I continued to work on the research paper and I joined the Behavioural Sciences Team for their fortnightly team meeting. They discussed their most recent research, both ongoing and recently completed, and had a guest speaker talk about an interesting topic. The guest speaker did a presentation on priority setting partnership in inherited retinal diseases. A priority setting partnership involves developing research in conjunction with those affected by it, in particular considering: What questions do they want answered? What areas of research do they want focused on? Contrary to expectations, patients are not always focused on the cure of the disease. They also have lots of questions about prevention, diagnosis and resources to help cope with the disease or explain the disease to children.

For inherited retinal diseases, they have the additional difficulty of thinking about how to include disadvantaged groups in research. In this case many or most of the patients are blind or deafblind. This means they have to make questionnaires online suitable for those with screen readers, for example by using high contrast and easy to read fonts, and avoiding bold, italics and underlining. They also often reverse black and white (e.g. use a black background and white text) to avoid overstimulation, minimise the number of words used (as many people read one word at a time), and avoid graphics and colours. They have to make the questionnaire as inclusive as possible, even for those most severely affected, otherwise research biases towards those with mild disease. While not directly related to my Churchill Fellowship project, I found this talk really interesting and it opened up a completely new perspective on inclusivity in research for me.

After a long week of meetings and research, it was finally the weekend, and we took the opportunity to travel outside of Sydney to the Blue Mountains for a relaxing weekend of hiking and nature.



Blue Mountains, New South Wales

Back in Sydney again, after a lovely weekend, I had a catch-up meeting with Dr Sansom-Daly and her researcher Holly Evans on 18th March 2024. We talked through the process they went through for designing Voicing My Choices Australia. Dr Sansom-Daly had got the idea for VMC Australia after doing a placement with Dr Lori Weiner in the US during her PhD. They started developing it in 2015, when they applied for ethical approval, which was granted. The study protocol was designed around Lori Weiner's original study design. They used a multi-stage design with mixed methods analysis (qualitative and quantitative analysis).

Stage 1 involved healthcare professionals, AYA patients (mostly survivors), parents of survivors/patients and bereaved parents. It was all done in Sydney Children's Hospital and Prince of Wales Hospital in Sydney. The participants were shown each page of Voicing My Choices US and asked:

1. How helpful do you find it?
2. How stressful is it?
3. Is there anything you would add, remove or change?

They were also asked:

4. How do you see this being used in practice?
5. What is your experience of these kinds of conversations?

Then they analysed the data and made changes to Voicing My Choices based on the responses, using clinical judgement and experience of working in the field. During this stage, the US version was updated with new sections such as:

- What I want for my children.
- What should be done with my social media accounts.

The team decided to carry on with the study and include these new sections in the Australian version. After stage 1, they developed the first draft of Voicing My Choices Australia, and later published the full information on the cultural adaptation process (Evans et al., 2023).

Stage 2 took place around 2019-2020, and involved think aloud cognitive interviews (mostly over the telephone due to Covid-19), where they put the new Australian version to AYAs only. They used questions as prompts, for example: What do you think when you look through the booklet? Following these interviews new changes were suggested. This stage also included questions about the visual appearance of the booklet, and changes to the appearance and graphics were made.

Stage 3 is the current stage of research and is ongoing now. For this stage they are collaborating with Dr Anthony Herbert in Brisbane and the Australian Medical Association of Queensland. They also used their in-house graphic designer to design the booklet. The interviews for this round will involve AYAs being given the new Australian tool. They will be all new interviewees and it will be done across 5-6 sites in NSW and QLD. They will also be told the background to the methods of development of it. They will be asked the same questions as at stages 1 and 2:

1. How helpful is it?
2. How stressful is it?
3. Anything you would add or remove?

They are planning to recruit AYAs only and ideally current patients (the target audience for the VMC tool). After the interview there will be follow-up questions 1 month later which include: Have you thought about the tool? Have you discussed it with anyone else? For this stage there is also an ecological momentary assessment questionnaire. This is a phone app which prompts them to answer questions at the same time of day, every day for 14 days.

After discussing the development of VMC Australia, we also discussed a recent paper published by Lori Weiner, a large-scale evaluation of the US tool, which found improved scores relating to patient response to planning their care when cure was no longer possible, after using VMC (Weiner et al., 2021). Dr Sansom- Daly also suggested that if I wish to develop a VMC UK version, we could start work at Stage 2 of the Australian study, and use the Australian version in think aloud cognitive interviews, as well as collecting data on how we envision it being used in practice. Following on from this we reviewed the progress I had made in writing up the research paper, including new ways to analyse the data and looking for journals we could submit to.

The following day was a much-needed rest day, when I had the opportunity to climb the Sydney Harbour Bridge, and also spent some time reviewing my meeting notes and planning the rest of the trip.

Sydney Harbour Bridge Climb, March 2024

Paediatric Palliative Care Team, Sydney Children's Hospital

The next day, I joined the Sydney Children's Hospital Paediatric Palliative Care weekly MDT, and met the whole team, including clinicians, social workers and physiotherapists. They discussed all their patients including inpatients, new referrals, unstable patients in the community, those in hospice and those who had recently passed away. For each patient they discussed medical issues, social issues and an action plan. They also discussed team education opportunities, planned teaching days and funding allocations. The meeting was held on Level 8 of the Bright Alliance Building, with incredible views down to the sea and into the city.

Level 8, Bright Alliance Building, Prince of Wales Hospital, Sydney

Following on from this I had a meeting with Dr Susan Trethewie, the Head of Paediatric Palliative Care at Sydney Children's Hospital. We discussed advanced care planning tools they use. She said that they ask parents about their goals before the clinic so they have an idea of their priorities and what memories they want to make, and that they most commonly use Canuck Place's 'Serious Illness Conversations' (Paediatric Version), as a tool for leading these conversations. This was really interesting as the second half of my research trip is to Canada where I will be spending some time at Canuck Place in Vancouver.

We then discussed the education of their healthcare professionals and how this is structured. They have Quocca educators for paediatric palliative care, whose role is to provide education for HCPs. The paediatric palliative care team also take trainees from other specialties for longer fellowships (e.g. general paediatrics/ICU) and shorter periods of observation, and provide education sessions in the ICU for the team working there. They would like in the future to have a full-time educator position. They run a quarterly national education session of 1.5 hours, which is aimed at medical professionals only. She also told me about Project Echo, run by Palliative Care Canada, which offers a structured learning process in paediatric palliative care for anybody interested in the area internationally.

Later I met with Dr Sansom-Daly and Holly Evans again and discussed the progress and next steps for the research paper. We discussed the structure of the results section, further ways to subdivide the results based on the participants' discipline or years of experience, visual representations of the results, limitations of the study and selected a shortlist of target journals. After this we went for a farewell team lunch in the hospital cafe and took some photos, as it was my last day at Sydney Children's Hospital.

Left: Dr Sansom-Daly and I Outside Sydney Children's Hospital, Right: The Atrium and Welcome Desk at Sydney Children's Hospital

Bear Cottage, Manly

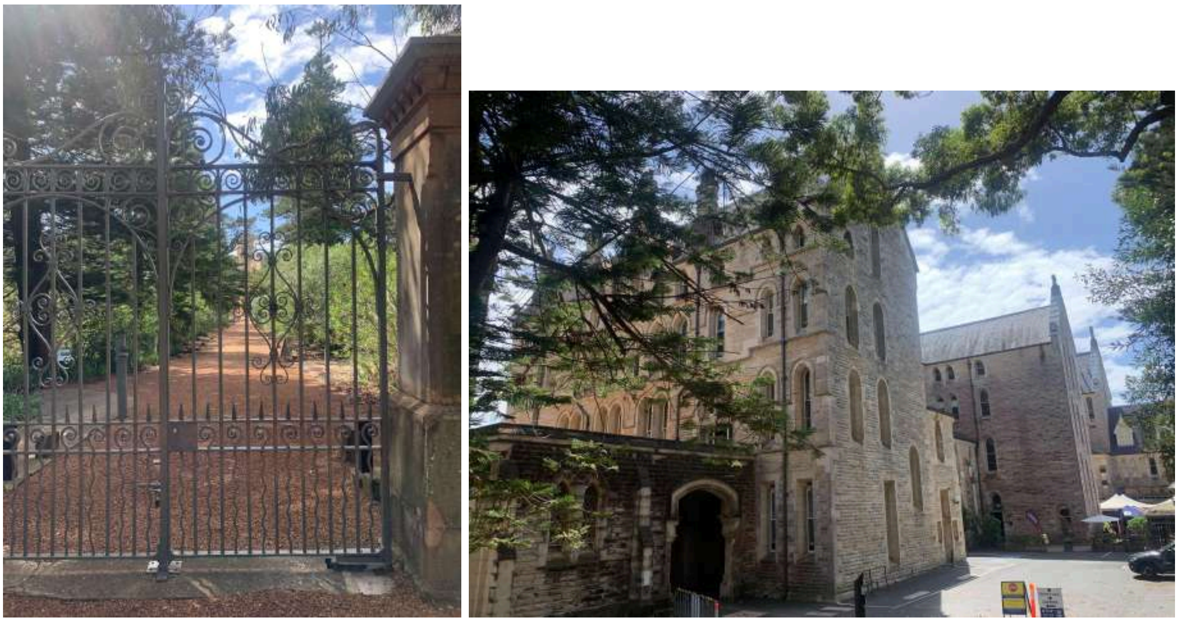
On my final day in Sydney, I was able to visit the paediatric and the adolescent hospices out in Manly (Northern Beaches). This required a beautiful 20-minute ferry ride through the harbour, which had amazing views of Sydney Harbour Bridge and Sydney Opera House.

Views from the Ferry Journey

I arrived in Manly, which has a much quieter, coastal feel to it, with a harbour on one side (where the ferry arrives) and a 2km beach on the other side.

Manly Harbour

I walked up from the Harbour to Bear Cottage, the Children’s Hospice, which is situated in the grounds of a former convent, in a leafy suburb. There I met Dr Nicole Armitage.



Former Convent and Location of Bear Cottage

First I had a tour of Bear Cottage, which has been set up to have a deliberately homely feel. None of the staff wear uniforms and they all use first names. There are different kinds of accommodation: units where families can stay together, rooms where the patient can stay alone, or rooms where the parents can stay on site but separate from the patient. All rooms have access to the outside, which has a tropical, rainforest feel. The family spaces are set up like holiday apartments and they have different configurations (such as double rooms, bunk bed rooms) and they can accommodate up to 6 adults in each family unit.

Bears Everywhere at Bear Cottage!

Family Apartments at Bear Cottage

From Bear Cottage, there is a path that leads directly to the beach. They wanted to give the hospice the feel of being on holiday, which is partly why the location was chosen.

Manly Beach

There is an amazing quiet room, which is raised up on stilts, has enormous glass windows and is surrounded by palm trees and rainforest, where they can have difficult conversations or families can go for a moment of tranquillity. They also have wonderful play facilities for the patients and families, as well as a spa area.

Garden Play Area and Spa

After the tour, I joined the team's weekly MDT meeting where they had a death review. This involved a multi-disciplinary meeting, joint with the NICU team, where they discussed a recent transfer to Bear Cottage of a 3 month old baby with multiple congenital anomalies, what went well and any learning points for both teams. They then discussed the current inpatients and the plans for admission and discharge over the next week. They had a new referral that morning for a baby, born to an Aboriginal family, who had died in the NICU overnight, who they could potentially transfer in to use the ‘cold room’ (a cooled room for a child to stay for up to 3 days after they have died), so the parents could spend some time with their baby. An interesting point of note in this case was that there are significant cultural differences in how Aboriginal people view death, that I had not been previously aware of. I felt this was something I knew little about and would like to research more.

AYA Hospice, Manly

After this I went to the AYA hospice that was located further up the hill and on the headland in Manly. It is on the site of the now-disused Manly Hospital, which had a slightly eerie and abandoned feel when walking up to it.

Former site of Manly Hospital

However, the hospice itself is an incredible, modern building, opened only a year ago. Designed in collaboration with AYAs, who felt it should feel like a hotel, everything is sleek, minimalist and modern.

AYA Hospice, Manly

Patients didn't want it to feel like a hospital/hospice and this was taken into account with the design. For example, the oxygen and monitoring can be hidden in the wooden panel at the head of the bed, and the hoist, which covers the whole room and bathroom, can be tucked away in the wardrobe. Due to its position on the headland, it also has incredible sweeping views of the water and the Sydney skyline.

View From the AYA Hospice Over Sydney Skyline

The facilities are also varied and aim to appeal to anything the young person could be interested in. They include a games room, a sensory room and a peaceful garden, where wildlife from the nearby Sydney Harbour National Park can be spotted (including echidna and bandicoots).

Games Room, AYA Hospice

Sensory Room, AYA Hospice

Garden, AYA Hospice

Overall it was an amazing facility that really has the patient at the heart of everything they do. What an incredible resource for AYA patients in Sydney.

Part 2: Brisbane

With the first part of my Australian research trip over, I flew to Brisbane on 22nd March 2024. As it was the weekend when we arrived, we took the opportunity to visit Noosa National Park, a short drive north of Brisbane on the Sunshine Coast, although it wasn't very sunny for us.

Noosa National Park

We then travelled back to Brisbane, staying in the heart of the city in the South Bank, which has a wonderful parkland, complete with artificial beach.

Brisbane South Bank

Paediatric Palliative Care Team, Queensland Children's Hospital

On my first day in Queensland Children's Hospital, I was met by Abigail, one of the nurse specialists in children's palliative care. She gave me a tour of the hospital and took me to meet the team where they were doing their morning huddle (discussing brief updates on their current patients).

Queensland Children's Hospital

Incredible Lego Model of QCH, Situated in the Hospital Atrium

After this I joined the paediatric palliative care team's weekly MDT where they discussed all their current patients, focusing on inpatients and those in the community who were struggling with symptoms or close to end-of-life care. This discussion included suggesting which patients might benefit from using Voicing My Choices and who could be recruited to the study that is being led by Dr Sansom-Daly.

Following this was their team journal club, which they refer to as the Journey Club. The main focus of this meeting is to improve care, usually by discussing a recent or interesting journal article, but any topics may be suggested that will help them deliver excellent care. This week it was an Easter special led by the Chaplain, involving quizzes and Easter-based games. It felt almost like Christmas in the UK, with palpable excitement for the upcoming Bank Holiday weekend.

This was followed by a team lunch, which they invited me to join. Everyone had strong opinions about where they served the best lunch near QCH, and in the end the consultant was overruled and we went to a Mexican cafe.

QCH Paediatric Palliative Care Team

In the afternoon I joined the team for the ward round of current inpatients, which involved seeing them on the wards, reviewing their medications, discussing any issues/concerns they have and making a plan for the rest of the week.

Alyson Grundy, Allied Health Lead for the Paediatric Palliative Care Outreach Collaborative

The following day I met with Alyson Grundy, a former social worker, who now works in paediatric palliative care research, who is passionate about using Voicing My Choices. We discussed the recruitment for the study on Voicing My Choices, which they are currently partaking in at QCH, and barriers to using the tool. She said the most common reason for avoiding its use is concern about taking away hope. For example, the patient we had discussed the previous day in the MDT and suggested she would be a good candidate for using VMC, some members of the team expressed concern about taking away hope when treatment was still aimed at cure. We then talked about how we live in a death-denying society, which makes it harder to talk about end-of-life wishes and care, and that having the conversation about it is more important than using the tool; however, tools help us to initiate the conversations we are uncomfortable with.

We then talked about a recent surprising case where VMC Australia had been used. In a very remote and rural community, they had a 16 year old patient with Rett syndrome, who has lots of physical and complex health needs. The carer sat down and did VMC with her using eye-gaze technology for communication, which required significant time, energy and commitment, as it took multiple sittings. Alyson also spoke about a paediatric case of a girl as young as 3 years old being able to articulate her wishes, and needing to listen to the voices of these younger children as well.

She referred me to other resources that they use for capturing end-of-life wishes, including the game ‘Hello’, the chatterbox tool and the sheet of conversation starters that they use, all of which acts as a non-threatening way to start conversations about this topic with the medical team, friends and family. The ‘Hello’ game can be found here:

https://commonpractice.com/products/hello-game

We then talked about voluntary assisted dying legislation in Australia, which has been present in Victoria for a while, but was only introduced in Queensland last year, and what this means for paediatric patients. It isn’t currently available to under-18s, but they have seen cases of health-literate AYAs who have accessed voluntary assisted dying when they turn 18, and the healthcare team have found this somewhat distressing, but in some cases, it is the right thing to do as it allows them to provide patient-centred, compassionate care. We finished the meeting, with some resources to look at in the future, including the Palliative Care Australia online learning modules for paediatric palliative care, including one specifically for advanced care planning, which can be accessed at:

https://palliativecareeducation.com.au/course/index.php?categoryid=42

It was easy to see that Alyson was extremely passionate about hearing children’s voices and helping provide the best possible palliative care to them.

Hummingbird House Children’s Hospice

The following day I went out to the northern suburb of Brisbane, Chermside, to meet the team and see the facilities at Hummingbird House children’s hospice. First thing in the morning, I joined the MDT, which included discussion of current inpatients and preparations for the Bank Holiday weekend, as well as planned admissions upcoming over the next week. Each patient, when they first meet the team, has a ‘Hopes and Needs Assessment’ to get to know them better and before an admission has a phone call to find out about them and their current needs and their goals for admission.

After the MDT we discussed the facilities and opportunities available at Hummingbird House and I had a tour of their incredible facilities. Hummingbird House is Queensland’s only children’s hospice, one of only three children’s hospices in Australia and was built around 8 years ago. They have facilities for 8 children, but usually have a maximum of 6 inpatients at a time. They have the upper floor with patient rooms, some with adjoining rooms for families. Downstairs they have 5 family suites that sleep up to 6 people in different configurations. They offer a range of admission types including end-of-life care, respite care and stays for families from out of the region who need to attend local appointments.

Hummingbird House Exterior

Lego Model of Hummingbird House in the Atrium

They have wonderful outdoor spaces including a lovely garden with play areas for the children and siblings, which are wheelchair accessible.

Hummingbird House Garden

Outside Play Area

Tree House

They also have a large rooftop terrace which they use for parties and events and they have even held a wedding here for parents of a child that was having end-of-life care.

Rooftop Terrace

They also have a wonderful hydrotherapy pool which is enjoyed by the guests and their families. Many patients who require a wheelchair have found it very freeing to be able to use the pool. On the day of my visit they had their therapy dog visiting, who saw all the inpatients. Here he is having a break from work in the garden and playing with a ball.

Therapy Dog

After my day at Hummingbird House, it was the Easter Bank Holiday weekend, and we took the opportunity to soak up some sun on the Gold Coast. I also had the opportunity to fulfil a lifelong dream of holding and feeding a koala, at a sanctuary nearby.

Gold Coast Beach

Feeding a koala

Kirsty Wedmore, Canteen Australia

After a wonderful weekend, we travelled back to Brisbane, and I met with Kirsty Wedmore from Canteen, an Australian charity which supports young people affected by cancer. The Queensland office looks after approximately 200 young people and holds events every 6 weeks. The role of Canteen is to support patients and families. This is done through therapeutic support, which is counselling (usually held in one-to-one sessions) and includes patients at the end of their life, current patients, cancer survivors, those who have parents with cancer or have lost parents to cancer. However, the main work is done through recreational support, which includes winter and summer retreats of up to 40 people. The last winter retreat was to Threadbow, near Canberra, for a ski trip and the last summer retreat was to Cairns to see the Great Barrier Reef. Examples of other events they hold include: whale-watching, dry paint and sip, and Japanese cookery. The events are led by young people and they are asked what they want to do. They also hold a 3-day camp every year per state and overnight programmes 5-7 times a year.

One of their main focuses is to help clients create continuing bonds with people who have gone through what they have. In particular, many patients found it hard to make friends in hospital because they were so ill, but find it helpful to connect with other young people who've been through cancer treatment once they are feeling better.

Canteen also help with end-of-life therapy, in terms of facilitating closing conversations and talking about what people want to leave behind. They help them find opportunities to have these conversations and support them with this, help them lift meaning out of relationships and tell people things they want them to know. If they wish, they help patients create something to leave behind - e.g. make a scrapbook of photos or playlist of songs. One patient decided to make bowls for each of their family members, which was a creative outlet for her and something that would trigger memories of her. Canteen try to guide patients through other issues they face including death anxiety, thinking about what they want their death to be like and living well while they can.

We discussed the difficulties that families face when they have a young person undergoing cancer treatment, for example, the family may have to move to Brisbane, and siblings go to hospital school. Or, many times, the young person and their mother move to Brisbane and father stays at home with siblings, which creates a very big divide and an emotional and financial strain on families. There are other charities which support this, for example Little Wings, a private plane company who collect patients and bring them to cities for treatment and appointments.

Tanya Quinn, Aboriginal Worker (Paediatric Palliative Care Team)

My last meeting of the Brisbane leg of my research was with Tanya Quinn, the Aboriginal worker for the paediatric palliative care team. I was interested to meet her to learn more about the cultural differences in the Aboriginal community and how they are supported by the palliative care team. She said that she has been in the role 4.5 years and it was the first of its kind in Paediatrics in Australia. She mostly focuses on education and advocacy work, educating hospital colleagues and allied teams to help them provide culturally appropriate care.

She told me that many Aboriginal people view death differently. They refer to death as 'going to spirit' and she has been given permission from elders to perform a ceremony to help the child's spirit transition without them being scared. Aboriginal people believe that they are part of mother earth and, linked to this, traditionally they are buried after death. The 80%

water that makes up our bodies become the streams and the rest becomes the earth and food for animals. Recently there has been an increase in Aboriginal people choosing cremation. This bond to mother earth also means that it is important for patients to go home when the child is well between rounds of treatment as it allows them to touch their motherland and get stronger.

Cultural practices are also affected by where they live, and Aboriginal people may live remotely or in the bush, in communities of around 1,000 people; there are country communities, which are closer to cities and may have around 20,000 people; and there are Aboriginal people who live in cities. Tanya goes to all the funerals (which are referred to as ‘sorry business’) of Aboriginal patients who have passed away, no matter how far away they are. She also stays in touch with families for as long as they want her to afterwards.

She said that there is still lots of racial profiling of Aboriginal people, but there are some positive changes being made. There are now Aboriginal workers across various teams in the hospital and they are planning to hire an educational officer. 2023 also saw the first Director of Aboriginal Health appointed, who sits on the hospital’s board of directors.

With the end of that meeting, the Australian part of my research abroad was finished and I flew home to the UK, to digest and write up everything I had learnt while I was there.

Findings: Canada

Part 1: Vancouver

I arrived in Vancouver on a rainy weekend, and as we had a couple of days before my meetings started in Vancouver, we took the ferry to Vancouver Island and spent some time enjoying rainy walks and beautiful beaches.

Vancouver Island

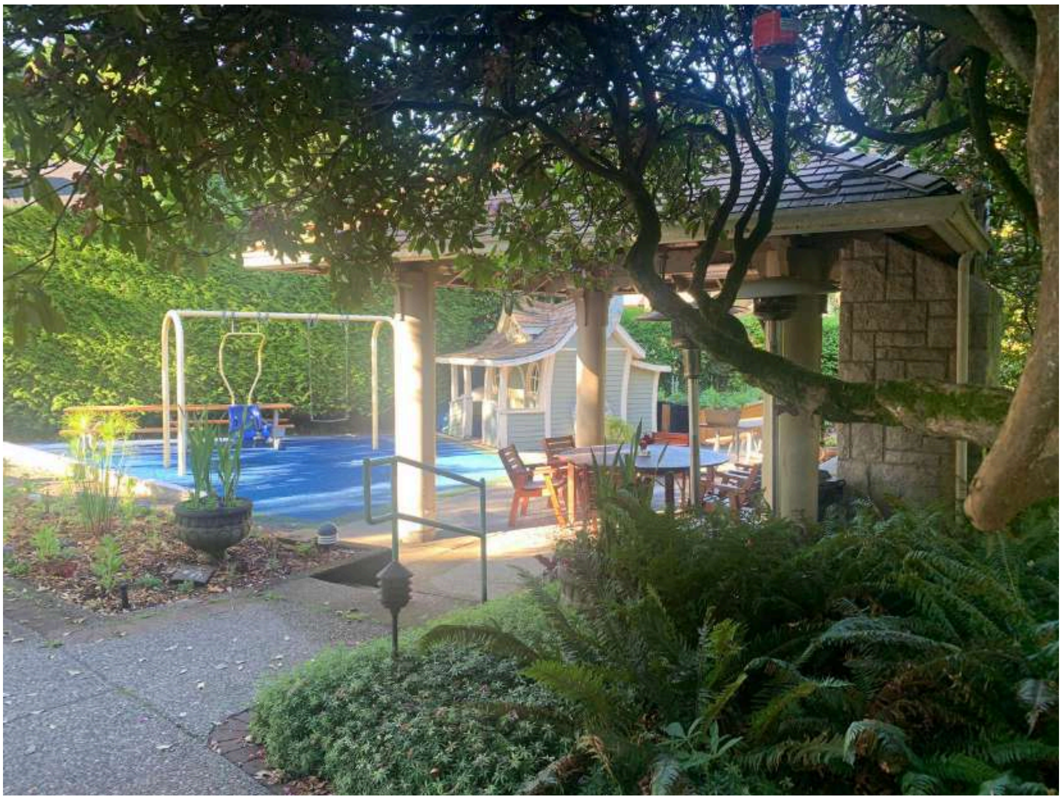
Dr Hal Siden, Canuck Place Children's Hospice, Vancouver

On my first day at Canuck Place I arrived at 8:30 am and joined the team's morning huddle where they catch up about the patients who are unwell or need more support in the community. After this, I had a meeting with Dr Hal Siden, the medical director and my main point of contact, about communication tools that they use for advanced care planning. They often use the PESST (physical, emotional, social, spiritual and trajectory) model to guide their conversations with families as it ensures that they have structure to the meetings, and they don't miss any aspect of the patient's life or care. They often start with discussion of physical symptoms, and once they have built a rapport move into the emotional and social aspects and then they use trajectory to lead into conversations about resuscitation and ceilings of care. He then suggested that I join a family–team meeting being held that morning where they would use the PESST model so I could see it in action. Later in my visit I could connect with Camara, the lead nurse, who has developed a serious illness conversation guide and associated education programme.

We then discussed the structure of training for paediatricians in Canada. They complete four years of undergraduate education, then four years of medical school, then do a four-year paediatric residency after which they can do a further two-year fellowship in paediatric palliative care. This fellowship is currently only offered by two centres, in Vancouver and Ottawa. However, Toronto and Alberta (Calgary and Edmonton) are currently developing their own programmes. As well as this, they also offer shorter-term fellowships to paediatric residents who come to the hospice for a month and learn about the work they do there.

We also discussed the history of the building which was really interesting. It is a large detached home, built in 1911, in a beautiful suburb of South Vancouver. It was donated to the city on the death of the last owner with the provision that something good would be done with it. At the same time, a nurse called Brenda, who had worked with Helen House in the UK, was trying to establish a paediatric hospice in Vancouver and connected with the mayor of Vancouver, who offered her the building to use. They currently rent the building from the city for $1 every five years, and the garden, which was owned by another family and was donated to them. They got the funding by working with a number of businesses and the Vancouver Canucks (Vancouver's National Hockey League ice hockey team) from which the name comes.

Canuck Place Main Building



Canuck Place Garden

Canuck Place Great Room

After this I was able to join their family–team meeting with the parents of a newly admitted patient. The patient was a 3 month old girl who had heart surgery shortly after birth and then difficulty with new neurological symptoms after this. She was found to have a brain tumour and subsequently underwent one round of chemotherapy from which she had significant side effects with little improvement in her cancer. After this they decided to transition to palliative/comfort care and she was transferred to Canuck Place the day before this meeting. The meeting followed the structure of the PESST model and focused mainly on her symptom management, goals for care and likely trajectory. I found it really useful to observe as the team had a really nice structured approach to discussing all aspects of care while allowing flexibility for the parents to take the conversation in any direction they wanted to. Referring to the PESST tool was used to help the parents understand the purpose and structure of the conversation and the team allowed them to focus on the most important aspects/issues they had. There was also excellent use of the MDT with the counsellor leading on emotional aspects and the doctors leading on medical issues and plans. I felt the overall conversation went really well and the parents seemed appreciative of the chance to express their feelings and wishes and it seemed that the team and the parents would all be on the same page moving forward. In the afternoon I accompanied the palliative care team to British Columbia Children's Hospital to review the inpatients that they are looking after. This mainly focused on symptom management and getting updates from the main teams about prognosis and input required from the palliative care team.

British Columbia Children's Hospital

On the next day, I met the team in the PICU for rounds so that we could meet the family of a 2 year old girl with haemophagocytic lymphohistiocytosis (HLH), a condition in which the immune system attacks the body's organs. She was currently still receiving full active treatment, but the PICU team felt she was seriously ill and that an introduction from our team at this point would be helpful as there may come a point where they transitioned to comfort care. After that, we checked in with a few other Canuck Place patients in the hospital and then headed back to the hospice.

Back at Canuck Place, I was able to sit in on a family–team meeting with the parents of a 2 week old girl who had been at Canuck Place for one week. She was born with significant bleeding on the brain and a significant brain injury as a result, so that she was felt to be unlikely to have any good quality of life. As a result, her parents had discussed options and decided to move to comfort care and been transferred to Canuck Place. The meeting was the weekly catch up between the team and the family and was centred around the PESST model. They mostly discussed the changes they had noticed in the last week and their feelings about this, in particular that she had lost some weight because she wasn’t feeding enough and that this made them distressed. The team were very reassuring that she wasn’t suffering and encouraged them to focus on the improvements since she came to hospice, for example that she had been awake more and they’d been able to interact with her more. Her parents sought reassurance that they could stay in the hospice as they needed, and the team was very encouraging that they take as much time as they needed. They also discussed their support system and which visitors they might find useful, as well as important memory-making opportunities. The parents felt that they would like to spend some quality time outside of the hospice but weren’t ready to go home yet. There was a discussion about making arrangements after she had passed away and they discussed both practical and spiritual aspects of this. Overall, it felt like a positive meeting and it seemed that the parents gained a lot of comfort and reassurance from it.

The next day, I started early at the PICU at BC Children’s Hospital to join their multi-disciplinary rounds on two patients. The first was the patient we saw the day before with HLH who had a further deterioration overnight. The second was a new admission of a 2 year old with near-drowning whose initial CT scan showed some changes which are likely to develop into a long-term severe brain injury. It was helpful to see how all the teams interact and how palliative care is introduced early so that if the transition to comfort care is required they have already met the families before, which makes it easier for both the palliative care team and the families to have difficult conversations about care.

Camara, Lead Nurse, Canuck Place Children’s Hospice

Later that day I walked back to Canuck Place (a beautiful tree-lined walk through a lovely neighbourhood) and met with Camara, the lead nurse, who has a special interest in communication and conversation around palliative care. We first spoke about the development of communication tools and the work of Dr Atul Gawande, a surgeon who developed checklists for theatre, and then when his father was dying, and he observed the palliative care team having serious illness conversations, he decided to create a tool to help all clinicians with having these conversations.

Camara told me about the work they had done developing a paediatric serious-illness conversation guide and the online education programme for this. She explained that the tool can’t be just picked up and used and that education is really important as it allows us to understand how it’s not just the questions that are important but how we listen, reflect and link the conversation into the next question. The primary purpose of this guide isn't to get to discussion of goals of care, but that it can be used to get to that point.

We also discussed their creation of the PMOST form (Paediatric Medical Order for Support at the End of Life), which documents the patient's resuscitation status and/or levels of care. This has been created from the adult form, which was much simpler as it was aimed at competent adults with capacity. They are using this both for patients who are not for resuscitation and for patients who are, as it helps families avoid difficult discussions about wanting full active treatment and resuscitation for their child every time they are admitted. We then discussed how they developed a 24-hour parent hotline that all families can access to speak to a senior nurse or clinician at Canuck Place. This helps provide comfort and support for parents who are looking after their children in the community. They can phone any time of day or night and speak to someone about anything from small questions about adjustments of medications to end of life worries or concerns. This provides a lot of reassurance for parents, especially those who are geographically located a long way from Canuck Place and it helps avoid some admissions to hospital. Additionally, if parents call and the decision is that they will go into hospital, the clinician receiving the call can either call ahead or attend the hospital themselves in order to make their admission smoother and make sure the family and patient wishes are followed.

We then discussed the Canadian assisted-dying programme, which is called MAID (medical assistance in dying), which was introduced in 2016. We discussed the difficulties that have arisen from this programme, including that culturally it has become thought of as a right and patients can therefore request it from any healthcare provider, which can create some moral and technical difficulties. She felt that this introduction has made it more difficult to provide good palliative care, as withdrawal, treatment or nutrition has become associated with the MAID programme, instead of their focus on providing comfort and avoiding unnecessary harm for patients who are dying. She feels this programme is likely to be developed for children as well in the future and this may bring its own difficulties for their work.

Cara, Spiritual Counselling Practitioner, Canuck Place Children's Hospice

Next I met with Cara, the spiritual counselling practitioner and one of three members of the on-site counselling team. They also have counsellors based at their other site and the team totals around 4 to 5 counsellors. We talked about how they structure their caseload and what a typical day looks like. As they are such a small team, they don't assign individual counsellors to each family but whoever is the clinical practitioner that day looks after the needs of any family that is staying at Canuck Place. In addition, they also look after all the families in the community and at BC Children's Hospital, which can be hundreds of families at any one time. We talked about the difficulties of the job and in particular she feels that their team finds it hard when families don't want to engage at all, as it feels difficult to identify what their needs are and how best to meet them. Conversely, what makes the job rewarding is when they feel like they are helping the families and patients at the most difficult time. She also said that it is hard when there is a language barrier and, even with interpreters, it can be difficult to build a rapport and sometimes it's hard to trust that the interpreter has conveyed the message as it was intended. We spoke about integrating their indigenous First Nations population and she explained that Canada is currently undergoing a reconciliation process and she feels that engineering change has been difficult and that they still have a long way to go.

Paediatric Morbidity and Mortality Meeting

My next meeting was attending the monthly paediatric morbidity and mortality meeting, where they discussed an interesting case. The patient had been diagnosed with an incurable cancer and as a consequence she had lost some of the physical abilities that she felt were essential to being herself. As a result, and as she had become an adult during the course of her treatment, she sought to end her life through medical assistance in dying (MAID). This had been a difficult case for the team, as it was the first time that one of their patients had chosen to end their life using MAID. As none of the healthcare professionals at Canuck Place were trained in MAID, they had to arrange for a specialist team to come in and perform the procedure. Both the Canuck Place team and the MAID team found this case really difficult because it was different from the cases they were used to. The Canuck Place team usually have younger paediatric patients who wouldn't be eligible for MAID and the MAID team were used to working with older adults. As a result, the Canuck Place counselling team had to provide psychological support for the MAID team who found the case extremely difficult.

Dr Marie-Claude Gregoire, Canuck Place Children's Hospice

Next I joined the weekly family–team meeting with the parents of the 2 week old baby who I met last week. This was a planned catch-up with the family to find out how things were going, how they were feeling and what their thoughts were about future plans. In particular, they were struggling with the difficulties around how much to feed her as she was feeding more frequently, yet still taking insufficient amounts to meet her needs. They were also having difficulty with the uncertainty of how much time she had left and where to spend it. They felt comfortable at Canuck Place and felt that it was easier to be there than to have to deal with the routine of home and the possibility of visitors. However, they felt that if the time with her was much longer, they would have to make a plan for when they would go home. This was especially the case because their 3-year-old daughter was staying with them at Canuck Place, and they felt they couldn't disrupt her normal routine for too much longer. They also had questions about what tests have been done to find out the cause of her illness, including genetic testing, and when they would get the results of this so they could make plans about the future. The team advised that they would look into this and talk to the team at the hospital and also mentioned that they could consider a post-mortem or further testing that could be done after she passed away.

I then joined the wider team for their weekly rounds, which involved meeting virtually with the teams at Canuck Place, the team at the other hospice in Abbotsford and the community teams. In this meeting we discussed the events of the last week, lit candles for the patients who had passed away, and discussed plans for the current inpatients, new referrals and the planned admissions. This was really interesting as I got to see how the wider team work together and how the two hospices share the patient load, for example transferring patients from the Canuck Place site to the Abbotsford site if that was closer to home for the families. It also allowed me to better understand their criteria for admission to their full programme and patients with temporary status, when they discussed their new referrals.

That concluded my time in Vancouver, which had been a very interesting and valuable learning experience. While there, we had also explored a bit of downtown Vancouver and the surrounding mountains, enjoying lots of walks in the sunshine.

Vancouver Skyline From Stanley Park

Lions Gate Bridge

The Harbour at Stanley Park

View From the Sea to Sky Gondola, Near Squamish, BC.

Granville Island From the Water

Part 2: Calgary

We arrived in Calgary at the end of the week and took the opportunity to spend the weekend in the nearby Rocky Mountains, doing some hiking and enjoying the outdoors, before starting at Rotary Flames House (RFH).

Banff National Park

Paediatric Palliative Care Team, Rotary Flames House (RFH), Calgary

Rotary Flames House in Calgary is a relatively modern building on the site of the Alberta Children's Hospital. It was gloriously sunny when I arrived early in the morning. I met Noelle Davis first of all, who works with the administrative team at Rotary Flames House.

She gave me a tour around the facility and then I met the team for the Monday morning handover. The house has two attendings (consultants) at a time, who cover the palliative care service. During my visit they were Dr Kevin Levere and Dr Mala Arasu who were both very nice and welcoming.

Rotary Flames House

We discussed the current patients, focusing on those who were most unwell. They had received a new referral for a young adult patient who had recently completed treatment for cancer and had been admitted to the hospital with a new mass. They felt it was likely to be cancer but were unable to do a biopsy as the patient had become too unwell. We also talked about a 2 month old baby staying in Rotary Flames House with benign tumours in his brain and spinal cord, which were expanding and causing neurological problems. After discussing all the patients, we then went to review this baby and discussed his progress with the family and their concerns and wishes for their time with their baby. We then visited another baby in the Children's Hospital, who has been diagnosed with a rare syndrome, which causes abnormalities of brain development. It is unfortunately a terminal illness with no cure and patients do not usually live longer than 1 year.

Alberta Children's Hospital

I next joined the team visiting the PICU to discuss their new referral of the young adult with suspected recurrence of her cancer. She had been stable but was clearly deteriorating quickly and her family felt that if it was possible, they would prefer to go home. The team agreed to look into her options for urgent transfer either to home or to her local hospital or hospice; however, as she was from a small rural farming community, this might be difficult. There were also concerns expressed by the oncology, PICU and palliative care teams that the delay in her diagnosis had made it more difficult for them to fulfil her final wishes as she had deteriorated so much in that time that she may not be stable enough for transfer.

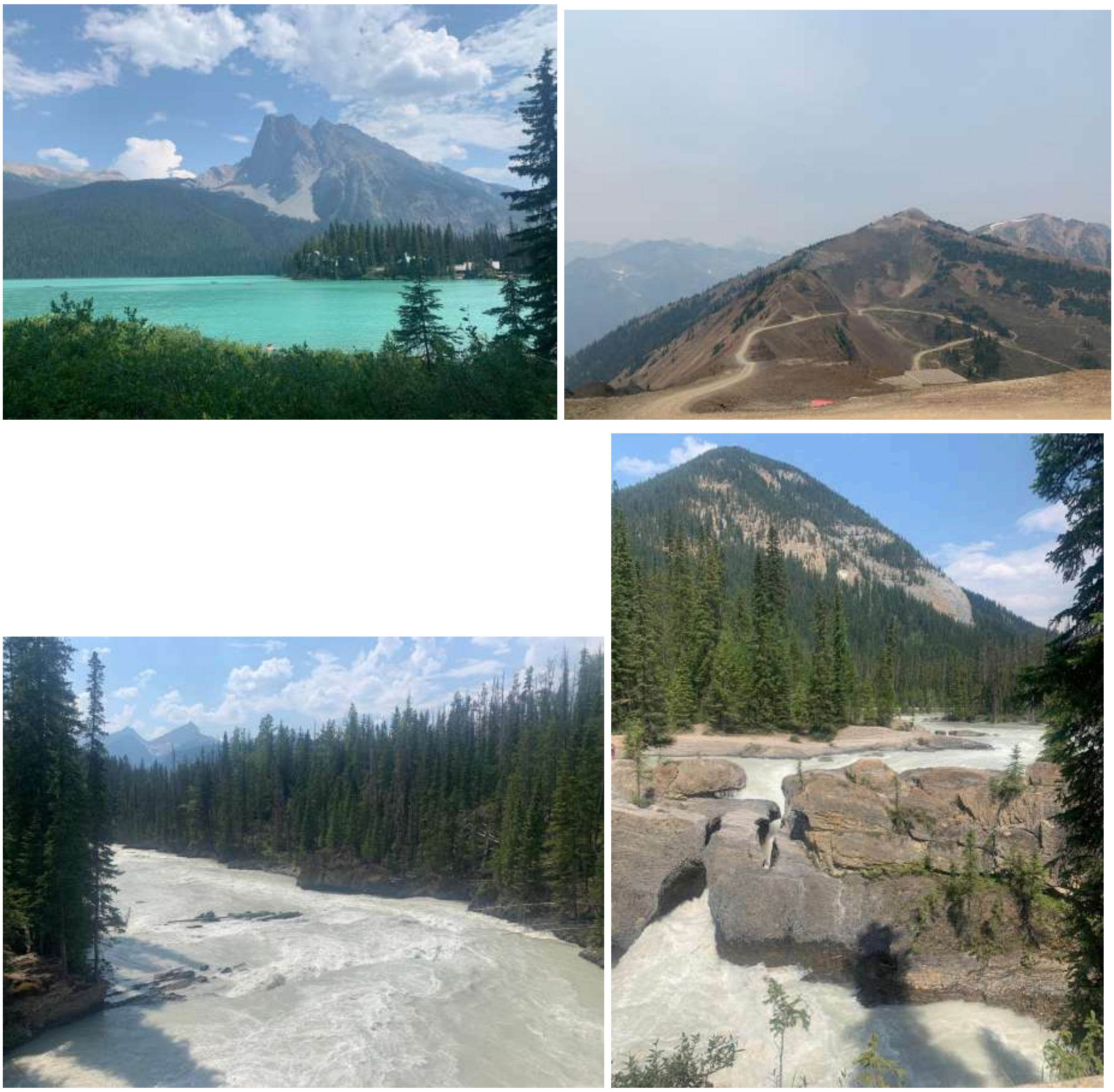
The next time I met the team, I was able to join their weekly multi-disciplinary rounds where they sit down and discuss all of their active patients at Rotary Flames House, at the hospital and in the community. The main focus of this meeting was to present the latest medical update, discuss the patient's current issues and trajectory, to share information within the different teams and make plans for the next week.

After this we went to Alberta Children's Hospital to review some of the other patients there whose care the team were involved in. These included an 11 year old patient with complications following a bone marrow transplant and a 15 year old with complex needs who had recently had a prolonged ICU stay following spinal surgery. This had made his care much more difficult for his mother who was his full-time carer. She had a meeting scheduled with the social care team the following day and the attending discussed strategies with her in order to help get the home care that she needs. One of the clinical nurse specialists from the team was also going to sit in on the meeting with her to be an advocate for her and the patient and to explain his complex medical and physical needs.

The next day I joined the team again for a catch-up about their patients. There hadn't been many changes with the patients staying at the house, so the team decided to divide up the patients to be seen at the hospital and review them. I went with the attending, Dr Levere to see two patients. First we joined the oncology team rounds (a sit-down meeting about all their patients) to catch up with the current medical status and plan for care of the patients the team was involved in. Then we saw the baby with the rare syndrome and the main purpose of the review was because the hospital was putting pressure on the team to admit the patient to RFH but the team felt that was not in line with the parents' wishes and the current goals of care. We discussed with the mother her feelings about the current level of care and monitoring and she advised that she was happy with it and that the monitoring brought her comfort as he was having pauses in his breathing that the monitor alerted her to, which allowed her to get some sleep. This monitoring isn't available at RFH, and this reassured the team that his current level of care was best provided in the hospital rather than at RFH. After this meeting we discussed the principle of making sure care is guided by the patient and where can best meet their needs rather than operational pressures, which is similar to our focus in the UK of always keeping the patient at the centre of care.

Next we saw an 11 year old girl with an underlying neurodevelopmental disorder who had been diagnosed with an inoperable brain tumour. Part of our visit to her was also to talk about options for location of care. We discussed her current plan with the oncology team, who were considering whether palliative radiation would be an option and had referred her to the radio-oncologist for review. Due to the risks involved in this treatment it was felt best that if this were to be an option, she should start this treatment first and ensure she was stable on it before going home or to RFH. However, if this was not an option or the family declined it, those options could be considered sooner. We then saw the patient with her mother, who explained that she was still considering radiotherapy and wasn't ready to discuss hospice care yet.

Overall, my time in Calgary was interesting and useful, and I saw many good examples of clinicians using good communication skills to have difficult discussions with patients and their families, as well as working closely with other teams to provide holistic and patient-centred care. We finished up our trip with another weekend in the mountains, this time visiting Yoho National Park before flying home to the UK on 24th July.



Yoho National Park

Recommendations

- Develop a UK version of Voicing My CHOiCES in collaboration with my interested colleagues across the UK. This should also be co-developed with teenagers and young adults who might use the tool and have a unique insight into how it would be helpful for them.
- In the next version of the CYPACP, include a section for additional relevant documents (e.g. does the patient have any other advanced care planning documents, like Voicing My CHOiCES).
- Propose that the Royal College of Paediatrics and Child Health include teenage and young adult palliative care as part of the core curriculum for paediatric trainee doctors in the UK. This could also be expanded to include other Royal Colleges working in associated specialities, e.g. Adult Intensive Care, Emergency Medicine, Adult Oncology.
- Explore the use of the Canadian paediatric serious-illness conversation guide and the online education programme associated with this as a tool for providing education for healthcare professionals in the UK around having difficult end-of-life discussions with teenagers and young adults.

Future Directions

Now that I've completed the overseas research for my Churchill Fellowship, I'm keen to put what I have learnt into action. Since returning from my travels I've been able to get involved in a number of different projects that will help further my goals in improving TYA palliative care. First, I have joined the Children and Young Person's Advanced Care Plan steering group, which is a national group of healthcare professionals and parents with lived experience, working together to improve the CYPACP document and resources around advanced care planning for children and young people. We had our first meeting on 14th October 2024 and I'm excited to be part of this group and to see how this work progresses.

Secondly, I have joined a committee who are organising both a national training day in 2025 in teenage and young adult palliative care and the palliative care content for the CCLG conference in 2025. These educational events will be focused on improving the understanding and practice of healthcare professionals in providing palliative and end-of-life care to children, teenagers and young adults with a life-limiting diagnosis.

I also think it is important to share the learning from my Churchill Fellowship with other healthcare professionals and colleagues in related fields, and I plan to do this by submitting my work for presentation at both the Children's Cancer and Leukaemia Group (CCLG) conference in 2025 and the biennial global Adolescent and Young Adult Cancer Congress in 2026.

I'm also keen to foster the connections with other healthcare professionals that I have made during my research. I will continue to work closely with Dr Sansom-Daly in Sydney and will contact Anne-Sophie Darlington in the UK, to establish whether collaboration would be possible.

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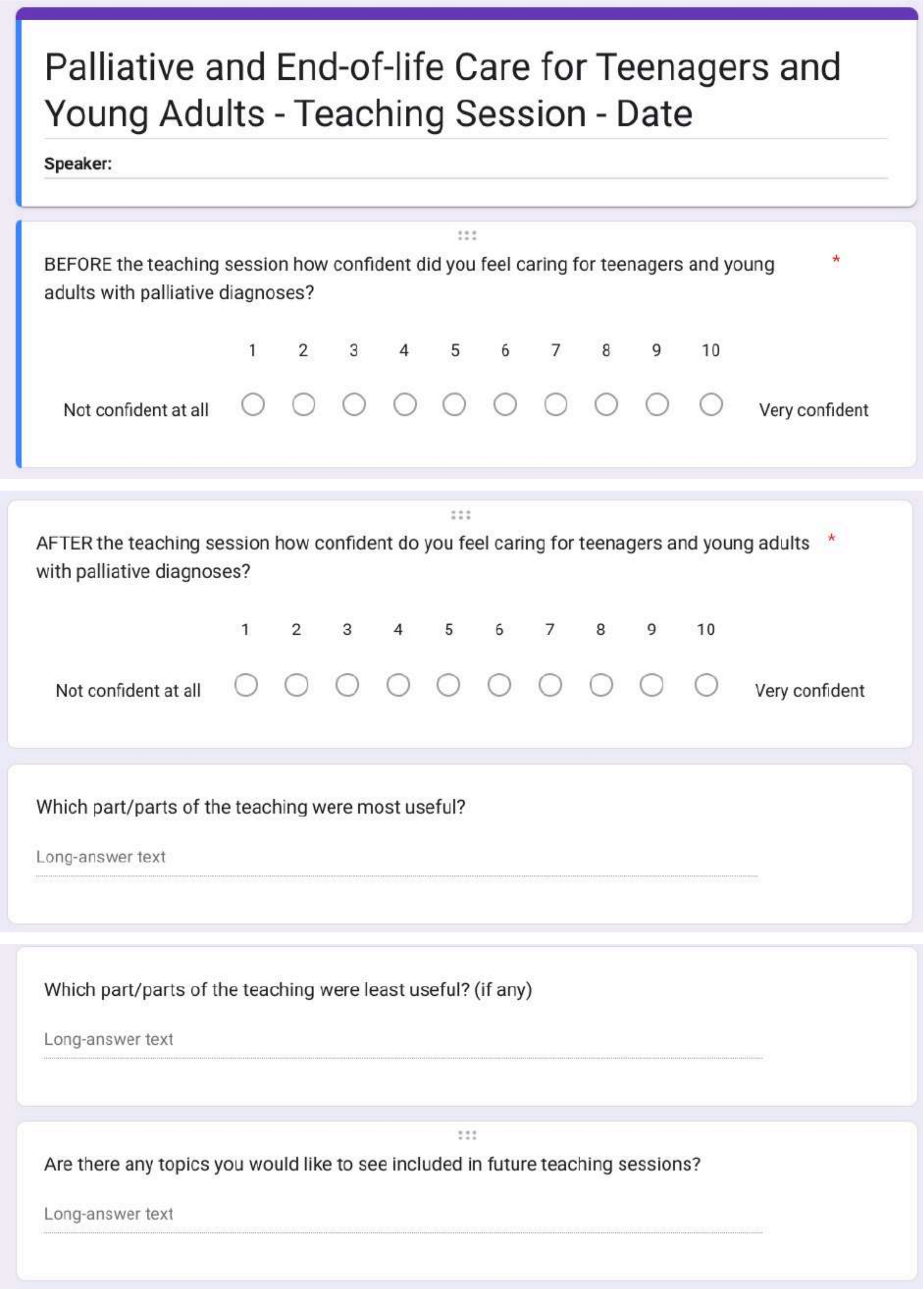
Appendix 1: Blank feedback form from teaching pilot scheme



Palliative and End-of-life Care for Teenagers and Young Adults - Teaching Session - Date

Speaker:

BEFORE the teaching session how confident did you feel caring for teenagers and young adults with palliative diagnoses? *

	1	2	3	4	5	6	7	8	9	10	
Not confident at all	○	○	○	○	○	○	○	○	○	○	Very confident

AFTER the teaching session how confident do you feel caring for teenagers and young adults with palliative diagnoses? *

	1	2	3	4	5	6	7	8	9	10	
Not confident at all	○	○	○	○	○	○	○	○	○	○	Very confident

Which part/parts of the teaching were most useful?

Long-answer text

Which part/parts of the teaching were least useful? (if any)

Long-answer text

Are there any topics you would like to see included in future teaching sessions?

Long-answer text

Appendix 2: CYPACP

Child and
Young Person's
Advance Care Plan

QR code

ID photo

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Plans can begin antenatally (using ante-natal version of this document) and are suitable for infants, children and young people

Name (baby, infant, child or young person):		**EDD** (if relevant)**:**	
Known as (if different):		**DOB:**	
Address including postcode:			
NHS no:		**Gender** (optional)	

ALLERGIES:

In emergency call:	
Other situations:	

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

See also Emergency Contacts on last page

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/Last review	

Irrespective of the ‘Date of plan’ it is good practice to check this still reflects current decisions / views, and to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see http://cypacp.uk/

http://cypacp.uk/
https://www.respectprocess.org.uk/

Version 5
Incorporating ReSPECT

Decision-making (additional to the ReSPECT document at the back)

First language		Interpreter required?	Yes ☐ No ☐
Information to help improve communication / support capacity:			
Decision-making details/preferences: For example - details of those involved if "looked after" child; others involved key family members/carers; how do child/family wish to be involved in decision-making?			
Important information relating to capacity and where further information can be found. Further guidance will be available on the CYPACP website. See also last page			

Clinicians have a duty to act in a patient's best interests at all times

Distribution list / Key contacts (*where available, please include out of hours numbers)

Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)

Name/Role/Department/Organisation and contact details:

		Name and contact details			Name and contact details
☐	Is there a regional central database?	Upload and note where this can be found:	☐	Respite/Short Break Care provider	
☐	Ambulance service		☐	School Nurse/Head Teacher	
☐	Lead Paediatrician/ Obstetrician		☐	Social Services	
☐	Palliative Team*		☐	Midwife	
☐	Hospice*		☐	Health Visitor	
☐	GP		☐	Other (eg Hospital Specialists)	
☐	GP out of hours (if different)		☐	Other	
☐	Children's Community Nursing*		☐	Other	
☐	Hospital (ward/ Assessment unit)		☐	Other	
☐	Local Emergency Department		☐	Other	

It is good practice to keep a copy of the Care Plan with the infant/child/young person at all times

Medical Background

Summary diagnoses / current situation:
Medical problems and background information (inc antenatal scans): Medical history, key moments in journey; previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan)

Personal Background

Personality/Quality of life when well: May help others recognise deterioration, targets for recovery. May also wish to document concerns about your/your child/s health now and for the future?
Tips to make infant/child/young person/yourself more comfortable: eg communication methods; particular likes; music; stories; play, etc. Please note where to find more detailed, separate care plans if relevant
Social/Psychological/Spiritual/Education support: (if felt to be helpful)
Family details: please include details of siblings, include family tree if helpful; other important family/friends/carers

Priorities/Goals/Values

Baby/infant/child/young person's wishes: Consider support to achieve everyday quality of life as well as special goals, eg place of care; spiritual wishes; goal-directed outcomes; what I most value/wish to avoid; legacy and memory-making during life
Family (including siblings) wishes: Consider how you as a family wish to be supported to achieve everyday quality of life as well as any special goals, eg where you want to be as a family; who to involve; sibling support and needs (eg medical, spiritual or cultural backgrounds); legacy and memory-making during life; what is most valued/wish to avoid.
Others' wishes: Wider family, school friends, carers

Wishes around End of Life

If it is recognised that your child/young person is nearing the end of their life, is there anything that would be important for us to know to provide the best care possible?

Priorities for care, including preferred place of care at the end of life and after death: Specify if preferred place of care at end of life is different to place of care after death.
Organ and tissue donation: See separate guidance on web link: https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/ National contact numbers: Referral line 0300 020 30 40 / General advice line: 0300 123 2323 Organ and tissue donation may be possible, but it depends on several factors. Specialists can guide on specifics should this option be considered
Spiritual and cultural wishes around death and dying: to include faith, beliefs and personal wishes such as music, family traditions and rituals
Memory and legacy making wishes (include family/siblings/friends if relevant) Consider how you/your child wish/es to be remembered which may include wishes for possessions and/or digital legacy.
Preparation/communication of process for management after death: 1. Consider required referrals (including sudden death and automatic Coroner referrals (eg HIE (hypoxic ischaemic encephalopathy); **2**. Need for regular medical review; **3**. Consider discussion and explanation of SUDIC process; **4**. In-dwelling devices and removal
Funeral preferences and bereavement support and other family preferences: eg preferred timing for removal of equipment from home. Seek detailed information or further advice if needed
If not discussed, it may be helpful to put specific reasons/context of why not: Note: No need to explain, but record if helpful to be aware of certain situations/circumstances

Management of Anticipated Complications/Deteriorating Health

Include reference to separate documents (and where to find) eg symptom management plan, specialty care plan(s). Please balance the risk (version control risk) of duplicating information already detailed in separate management plans whilst recognising this section can be very helpful for quick access in emergencies.
NOTE: For antenatal care plans – this section may be deferred (if desired) until assessment after birth.

General Management

Current course of medical treatment: eg disease directed therapy; clinical trials, etc
Notes on likely deterioration (if known and relevant): Consider likely cause(s) of deterioration, including signs, symptoms and red flags
Management of progressive deterioration (if different to general deterioration detailed below): It may be appropriate to refer to other sections such as priorities of care if end of life is recognised

Systems approach to managing deterioration

Airway: Tracheostomy (also note if patent upper airway) and airway adjuncts
Breathing: Oxygen, pressure and ventilation support
Circulation/cardiac: Access; diuretics; blood pressure support; implants – what patient has, when and how to change or turn off
Neurology: State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management
Management of commonly occurring infections: Including central line and stated temperatures for individual child
Nutrition and hydration: Including presence of, or discussion about NG, NJ PEG and JEJ, TPN
Blood tests: Consider frequency, indication and specific tests or stop routine tests
Blood products: Consider type, frequency and indication eg blood test or clinical symptoms
IV/SC access: Portacath; Hickman; Midline; other; and discussions about subcutaneous access
Condition specific interventions/general: not previously mentioned, may include when to call 999, transfer to hospital
Other patient plans/where to find: symptom management plans; specialty care plans (eg respiratory care plans), etc

Management of an Acute Significant Deterioration/Emergency

For review with **"Management of Anticipated Complications"/"ReSPECT"**
If end of life recognised, see **"Wishes around End of Life"** and consider transfer to preferred place. Allergies listed at front

In the event of a likely ***reversible*** cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis, please intervene and treat actively (irrespective of resuscitation wishes)**

Note any differences to plan detailed below if parents/carers are not present
If none recorded, assumption will be made to follow plan detailed below, even in absences of parent/carer

In the event of life-threatening event, provide the following care: add patient-specific detail below

				Comments (patient-specific decisions eg duration)
Basic Life Support	**Yes ☐**	**No ☐**	**Airway repositioning**	
	Yes ☐	**No ☐**	**Airway adjuncts**	
	Yes ☐	**No ☐**	**Bag and mask/tracheostomy** (also note if upper airway patent)/mouth to mouth ventilation	
	Yes ☐	**No ☐**	**Chest compressions**	
	Yes ☐	**No ☐**	**Defibrillation**	
Airway	Yes ☐	No ☐	Suction	
	Yes ☐	No ☐	Intubation/Supraglottic airway insertion (eg LMA)	
Breathing	Yes ☐	No ☐	Supplementary oxygen if available	
	Yes ☐	No ☐	Highflow (eg Optiflow/Vapotherm)	
	Yes ☐	No ☐	Non-invasive ventilation	
Circulation	Yes ☐	No ☐	Intravenous access	
	Yes ☐	No ☐	Intraosseous access	
	Yes ☐	No ☐	Cardiac/ALS drugs (usually in conjunction with chest compressions)	
Other	Yes ☐	No ☐	Emergency transfer to hospital	
	Yes ☐	No ☐	Consider Intensive Care admission	

Additional comments about the above decision or relevant other decisions

Please record details of implantable devices eg VNS/pacemaker/defibrillator, and management at end of life of these devices; long-term IV access; respiratory support (further details may be in separate care plans or

“Anticipated Complications” page (eg may include specific information if a life-threatening emergency happens at school). Consider revoking ACP for planned surgery, etc Include preferences of transfer, eg local hospital or specialist centre if more suitable (**Note:** preferences may not be possible depending upon situation and local policies. Consider how interventions will be carried out for emergency clinicians and on-going management plans

(as part of the CYPACP [Child and Young Person's Advance Care Plan]**)**

(Recommended Summary Plan for Emergency Care and Treatment Version 3)

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

1	**Preferred name:**		**Date completed:**	

2 Shared understanding of my health and current condition:

Summary of relevant information for this plan including **diagnosis** and **relevant personal circumstances:**

Details of other relevant planning documents and where to find them (eg Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency Plan for the carer):

I have a legal welfare proxy in place (eg registered welfare attorney; person with parental responsibility). If "yes" provide details in Section 8 Yes ☐ No ☐

3 What matters to me in decisions about my treatment and care in an emergency:

Prioritise sustaining life, even at the expense of some comfort	**Prioritise comfort,** even at the expense of sustaining life

How would you balance the priorities for your care?

What I most value:	What I most fear/wish to avoid:

4 Clinical recommendations for emergency care and treatment:

Prioritise extending life Clinician's signature	OR	Balance extending life with comfort and valued outcomes Clinician's signature	OR	Prioritise comfort Clinician's signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended	For modified CPR (Child and Young Person)	CPR attempts **NOT** recommended
Clinician's signature	Clinician's signature	Clinician's signature

5 Capacity and representation at time of completion (see also “Decision Making” section)

Does the person have sufficient capacity to participate in making the recommendations on this plan?	☐ Yes ☐ No	If “no” in what way does this person lack capacity? If the person lacks capacity, a ReSPECT conversation must take place with the family and/or legal welfare proxy
Document the full capacity assessment in the clinical record		

6 Involvement in making this plan

The clinician(s) signing this plan is/are confirmation that: (Select A, B or C, OR complete section D below):

A	☐		This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.
B	☐		This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.
C	☐		This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):
	☐	1	They have sufficient maturity and understanding to participate in making this plan.
	☐	2	They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
	☐	3	Those holding parental responsibility have been fully involved in discussing and making this plan.
D	If no other option has been selected, valid reasons must be stated here. (Document full explanation in clinical record):		

Record date, names and roles of those involved in decision-making, and where records of discussions can be found:

7 Clinicians’ signatures

Designation (grade/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature/image**	**Date/Time**

Senior responsible clinician:

Designation (grade/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature**	**Date/Time**

8 Emergency contacts and those involved in discussing this plan

Emergency contact name **(Primary contacts in purple)**	**Role/Relationship**	**24 hr contact** Tick if Yes	**Emergency contact number**	**Signature** (optional)
Patient/family:		☐		
Patient/family:		☐		
Professional:		☐		
Professional:		☐		
Professional:		☐		

9 Form reviewed (eg for change of care setting) and remains relevant

Review date	**Designation** (grade/specialty)	**Clinician name**	**GMC/NMC/HCPC Number**	**Signature**