

# SUPPORTING FAMILIES IMPACTED BY PARENTAL CANCER

2024 Churchill Fellow

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# EXECUTIVE SUMMARY

The aim of my research was to explore how the USA and Australia support children after their parent has been diagnosed with cancer. In these countries and within the UK, the cancer incidence rate is rising for people under 50, meaning a rise in children impacted by parental cancer (1-3).

I wanted to learn what types of effective support are put into place for affected families, how they are accessed and how the healthcare system integrates with the community.

## My key findings were




Children and teens have a better outcome if they understand their parent's illness and are given coping and communication tools and skills and engage with peer-to-peer support.

Support for a parent is critical at diagnosis, end of treatment or when there is a prognosis change and this needs to be easily accessed without complex referral processes.

Support for a family impacted by parental cancer is more effective if relevant organisations are coordinated and work together and are known to cancer healthcare professionals.

Age-appropriate cancer education in primary schools has an economic benefit by significantly reducing the need for children's mental health services.

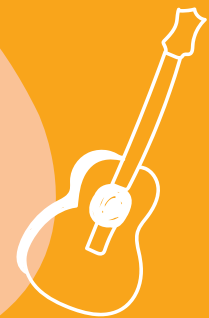
## My recommendations are



Provide training to the cancer healthcare workforce on the impact of parental cancer and make it mandatory at diagnosis for a patient to be asked if they have parental responsibility.

Fund and build a service that provides age-appropriate support for affected children that focuses on cancer education, learning coping skills and tools, and opportunities for peer-to-peer support.

Fund and build a service where parents diagnosed with cancer can easily access support based on their family's needs. This support needs to include psychoeducation, opportunities for peer-to-peer connection, and access to support for their children.



Create a more coherent support system for families impacted by cancer by strengthening the links between small and large cancer charities. Bring clarification around what each organisation can offer and encourage working together to create shared initiatives.

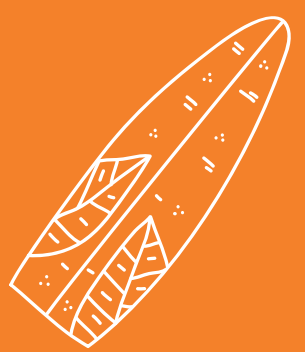
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# 1 BACKGROUND

In the UK, there is a lack of recognition, and therefore support for a cancer patient who has parental responsibilities. The parental role is not identified at the beginning of the cancer care pathway, and no formal training exists for cancer healthcare professionals around the impact that parental cancer can have on a family.

Evidence shows that parents feel wholly unsupported around telling their children of their cancer diagnosis and knowing how to support them (4). Studies show that children affected by parental cancer are at a higher risk of developing psychosocial problems, such as anxiety and depression (5). Patients look towards their nurses for guidance, but cancer healthcare professionals report an inadequacy of skills and are fearful about the potential consequences of communication (6).

The Department of Health and Social Care and large national cancer charities have been slow to acknowledge this need, overlooking the pivotal role of a parent and the negative outcomes of children's experiences when a parent is seriously ill.

Currently within the UK, there are five charitable organisations that specifically support families impacted by cancer on a national level. Fruit Fly Collective (7), who support parents diagnosed with cancer, The Ruth Strauss Foundation (8), who support families facing the death of a parent from cancer, Hope Support Services (9), who support 5-25 year old children when a loved one has a serious illness, Mummy's Star (10), who support a person diagnosed with cancer when pregnant, and The Osborne Trust (11), who support children impacted by parental cancer by providing respite activities.

There is no streamlined approach to accessing support. If a parent receives support from any of these organisations, it is likely because a well-informed nurse has signposted them.

## Who am I?

My dad died of cancer when I was 12 after a very short prognosis. No-one in my family understood what cancer was, and no support was given. As a consequence, I deeply buried my own grief, only for it to reappear when I became a mother 25 years later. Whilst processing this delayed grief, I learnt how the parental relationship is fundamental in enabling what a child can learn and how they engage with the world. With a research background in neurodegenerative diseases and science public engagement, I wondered why subjects like parental illnesses were not packaged up into colourful resources to help children who experience these illnesses in their family.

In 2012, I set up Fruit Fly Collective, to design age-appropriate resources for families when a parent has cancer. After years of piloting different projects, winning awards, building a team and establishing ourselves, we realised the biggest impact we could make, with the limited funding and resources we had, was to empower parents to support their own children. With the right information, guidance and evidence-based strategies, skills and tools, parents can navigate themselves and their children through the family life changes that parental cancer inevitably brings. We also knew it was critical to train up the health and social care professionals within the cancer care pathway.



## 2. WHO DID I CHOOSE TO VISIT AND WHY?



### Texas, USA | Wonders & Worries

Wonders & Worries (12) is a national charity based in Texas. Their aim is to support children under the age of 18 years when their parent is living with a serious illness or injury. 80% of their families are impacted by cancer. It was started 25 years ago when two Child Life Specialists (CLS) working in paediatric oncology were repeatedly being asked by colleagues in adult oncology to come and support the children of their adult patients. They recognised that their child life skills were needed in the community so set up Wonders & Worries. Wonders & Worries now employ over 60 CLSs who support over 1,300 children and parents per year in the US.

### Sydney, Canberra, Melbourne, Australia Canteen | Camp Quality Red Kite | Cancer Hub



Canteen (13) is a national charity that supports teenagers and young adults impacted by cancer because of their own diagnosis, their parent's or their sibling's. The charity was created because of the positive impact of a research focus group made up of young people with cancer.

Camp Quality (14) is a national charity that supports children aged 5-15 impacted by cancer because of their own or a family member's diagnosis. Their focus is bringing normal childhood joy to children, as well as cancer education.



Red Kite (15) is a national charity that supports children from 5-12 diagnosed with cancer and their families.

All three charities were established 40 years ago and because of their alignment supporting similar communities, they formed a partnership two years ago called the Cancer Hub (16). The Cancer Hub is a one-stop shop of support when a parent or child has been diagnosed with cancer.



## 3. OBJECTIVES

The aims of my overseas research were to explore how different organisations, operating in different societies with different healthcare systems, support families impacted by cancer. I wanted to find out about best practices, and what models of care might work in the UK.

### CAMP QUALITY'S SUPPORTIVE PROGRAMS AT EVERY STEP OF THE CANCER JOURNEY

| HOSPITAL PROGRAMS*  | RECREATION PROGRAMS                          | EDUCATION PROGRAMS   |
|---|--|--|
| CHILD LIFE THERAPY<br>BEDSIDE PUPPET<br>PLAYDATES<br>BEADS OF COURAGE<br>& STAR BEADS<br>PROGRAMS | FAMILY CAMPS<br>KIDS' CAMPS<br>VIRTUAL CAMPS | CANCER EDUCATION<br>PROGRAM<br>KIDS' GUIDE<br>TO CANCER<br>WEBSITE AND APP |
| FAMILY SUPPORT<br>GETAWAYS  | FAMILY DAY<br>ACTIVITIES                     | COUNSELLING &<br>SUPPORT   |
| FAMILY GETAWAYS<br>EMERGENCY<br>RESPITE   | FAMILY FUN DAYS<br>FAMILY EXPERIENCES        | CANCER HUB<br>NAVIGATION SERVICE<br>PARENT & CARER<br>COUNSELLING          |

### 1. Methods of supporting parents diagnosed with cancer

- Online versus in person; formal versus informal programmes
- Impact of individual support, group support, child-only support and whole family support
- Reaching and engaging diverse communities
- Peer to peer led models of support

### 2. Co-ordinating systems of support for a family impacted by parental cancer

- Interactions between the education, health, social and community sectors
- Acknowledgement of the parental role in the healthcare pathway

### 3. Education for those who support patients who are parents

- Training platforms and formats for healthcare providers
- Key training content delivered
- Successful ways to engage with stakeholders



The doors in hospices in Canberra have to have signs telling people to close them because the snakes come in!





# 4 MY FINDINGS



My findings are categorised into themes where I describe my learning and observations together with a brief analysis of how these are relevant to the UK, and any potential challenges of adoption.

## Theme 1: Supporting children impacted by parental cancer

### WONDERS & WORRIES CURRICULUM

Wonders & Worries' (W&W) main programme of work is delivering a six-week curriculum intervention for children from the ages of 5 to 18 years old, who have a parent living with a serious illness or injury. The intervention is delivered by Child Life Specialists (CLS) within a community setting. The curriculum covers illness education, understanding feelings, coping strategies, dealing with changes and exploring hope. An adapted version exists for teenagers, and another for when a parent has advanced cancer. It can be delivered either online or in person. A random controlled trial study (17) reported that both children and parents supported by this intervention showed improved psychological outcomes.

The sessions are delivered in person at W&W offices in Austin, San Antonio and Houston, or online. Parents drop off their children but are not invited into the session. The session is for the child, or siblings only and is a confidential space. The parents get a debrief after each session.

During my research I felt privileged that children, and their highly experienced CLSs, allowed me to observe some sessions. I witnessed extraordinary, individualist support that enabled each child to feel comfortable, nurtured and valued. There was space for their feelings, thoughts and behaviours, they were accepted without judgement, and without parental constraints. I strongly believe that if every affected child received this level of support the next generation would have better emotional health and would be better equipped to cope with life challenges.



### CASE 1

Observing a session with 4-year-old Zoe. Zoe's dad is very sick with throat cancer, diabetes and has become a leg amputee. In the playroom, we did medical play using the My Special Aflac Duck, the Playmobil hospital and costumes. My Special Aflac Duck is a social robot duck that comes with medical play equipment. It offers children comfort and helps them to express their emotions. Zoe was a very busy child who fired nerf guns at the wall. Zoe said she was sad about her dad being in hospital again whilst the CLS talked her through a Human Body book. She didn't want to say any more after that.



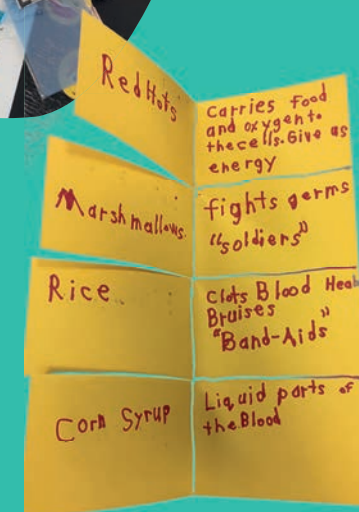
### CASE 2

Observing a session on coping and stress with 9-year-old Isabella whose mum is has stage IV breast cancer. She is a single mum who went away to be treated for 4 months, leaving Isabella with her grandad for part of that time. There have been lots of changes and transitions in Isabella's life. She was initially unsure whether I was allowed in the session, but I gained her trust by giving her a Terry's Chocolate Orange! Isabella didn't want to engage with any talk about feelings, so she signed the letter P on her palm which indicated it was personal so the CLS moved on. At the end they played with the Playmobil hospital. When the CLS asked why the bear was sick, Isabella said 'because he has had to move homes'. This gave a hint to the CLS about how Isabella is feeling, and the impact of her moving around the US with her mum for treatment.



### CASE 3

Observing the first 'getting to know you' session with Isla, a 15-year-old whose dad has stage IV colon cancer. We sat in the CLS office rather than the playroom. We did a 'getting to know you' game with Skittles. We each had a bag and emptied them on the desk and divided them into colours. Red = what makes you angry? Yellow = I'm happy when... Green = what makes you scared? Purple = what makes you sad? The final activity was sticking magazine cutouts that might represent who Isla is, onto a giant wooden jigsaw puzzle piece. During this activity the CLS asked Isla what she knew about her dad's cancer. Isla said she knew it was in the colon. She didn't know what staging meant but knew the treatment wasn't working. The CLS said that next week they would be learning about cancer.







**In the UK, health play specialists (equivalent to US CLS) work only with children impacted by their own illness. I reached out and discussed this with the Head of Play at Starlight (18) who revealed that they could not think of a programme in the UK where children impacted by their parent's illness were supported using play specialist skills.**

**It would be simple to provide this unique level of support in the UK - to train play therapists, or people qualified in children's mental health, to deliver the W&W six-week intervention, and embed them into every cancer hospital. Costs and infrastructure would be the main barriers for implementation, but we could look to existing spaces outside of hospitals, such as Maggie's Centres (19) that might have more capacity.**



## WONDERS & WORRIES CHILDREN SUPPORT GROUPS

Once the W&W curriculum is completed, children continue to be supported by attending monthly support groups that are delivered both in person and online. Children (6-11 years) and teens have separate age-appropriate support groups which are themed to embed their learning gained from the curriculum.

One evening I attended the support group for teens. It was October so this month was the popular Pumpkin Smash event. Ten teens of different ages, from different backgrounds, some who had been supported by W&W for years and some who were new, carved pumpkins with the staff. The stressors we were feeling were written on the outside of the pumpkin skin, and the gloopy seeds were spooned out, representing the importance of releasing difficult feelings from inside us. We then went outside into the parking lot and proceeded to smash our pumpkins with baseball bats, ice hockey sticks, hammers and mallets. A discussion followed looking at ideas around coping with stressors in safer ways (and outside of the pumpkin season!)



During this activity, the teens did not discuss with each other about how they were dealing with parental illness, but lots of stressors were written on pumpkins and lots of peer support was felt by just being together doing an activity in the same space. A testament to the impact of these support groups is that the teens show up month after month, year after year.



**Hope Support Services run online teen support groups but I'm unsure of their impact and I am not aware of any published data. I can assume that the success of the W&W teen support groups is because each teen has already built a relationship with the CLS staff so they feel comfortable, have a high level of trust, and understand there are no expectations on them.**





## CAMP QUALITY KICC (Kids Impacted by Carer's Cancer) CAMPS

The aim of the camps is to build children's confidence, strength and a sense of belonging, and be surrounded by peers who understand what they are going through. They are free and offered to children aged 7-13 years old. Virtual camps are also offered. In 2023, 456 kids received a 'Camp in a Box' containing different fun activities. The children could also log in to one of the three interactive live streamed sessions. This format breaks down the barrier of location, with children able to connect with each other from wherever they are in Australia.

**The camp culture does not really exist in the UK and going to summer camp is not a common childhood experience. Although UK children would benefit from these camps, it might be an easier culture shift to run day events for children or look at family weekend camps for the whole family.**

**Delivering virtual camps is an interesting idea as this is possible to implement and could run alongside virtual support for the parent. Parental illness can mean that many children do not get to experience extracurricular activities and therefore a virtual camp would be a great respite for some children.**

## Theme 2: Supporting parents diagnosed with cancer

### CANCER HUB CANCER NAVIGATORS



The most extensive level of parental support was demonstrated within the Cancer Hub's Cancer Navigator initiative. Parents who are referred to the Cancer Hub have their family's needs (emotional, financial, educational and practical) assessed by a Cancer Navigator (CN). The CN then works to get the family the support they need.



This could be anything from linking them to relevant local services, accessing financial support, or referring them on to Canteen's robotic student initiative. The Cancer Hub reported that 88% of Cancer Hub's parents felt overwhelmed with the number of referrals offered to them, and subsequently did not refer themselves to anything. CNs remove that burden by making the referrals, chasing them up and ensuring the families can easily access the support they need.

I was told several stories that captured the impact of the CN role. A dad needed to relocate with his son who was receiving treatment from a hospital out of town but was very concerned about the upkeep of his beehives. The CN was able to link up the local bee support group so they could look after his hives whilst he was away. Because of this personalised support, the dad trusted the charity and accessed their counselling sessions, an action he would not have taken before.

### CANTEEN PARENT SUPPORT WORKER PROJECT

In 2019, Canteen piloted a project (20) whereby they recruited staff with a social worker background to become a Parent Support Worker and embedded them within a hospital. Their role was to provide immediate support at diagnosis once a patient was identified as a parent. Support might be helping them navigate the services available to them, helping them tell their children about their cancer diagnosis, or helping them navigate being a parent whilst receiving treatment.

Although there were many challenges evaluating this project, the presence of a Parent Support Worker was shown to be an important form of support for parents at the critical time of their diagnosis. There was also a significant increase in the uptake of Canteen services as the Parent Support Worker was able to complete the referral. The role did not continue but in one of the hospitals an important change was introduced: they made it mandatory that a patient is identified as a parent in the first clinical consultation.

**These models of care show that parents diagnosed with cancer need timely support at diagnosis. They need the support to be tailored to their needs, and they need a professional to guide them, especially at crisis points. Identifying whether a patient is a parent at the first point of contact within the cancer healthcare system is such a simple process, but one that would have a huge impact on an entire family and cost the NHS next to nothing. Campaigning for this change is challenging, and NHS systems for documenting patient's details are complex and inconsistent.**

**The idea of creating a role within cancer clinics similar to the Parent Support Worker in the short term seems unfeasible in the UK. However, upskilling one member of staff, such as a Clinical Nurse Specialist, in each NHS hospital might be more achievable. In the UK, Shine Cancer Support (21) who support people with cancer in their 20s, 30s and 40s are piloting a new initiative called 'Shine Champions'. Healthcare professionals apply to receive in-person training and online masterclasses reflecting the needs of Shine's community. The aim is to have one champion within each hospital who can support patients within this age group. It will be interesting to see if the results of this pilot echo the findings from Canteen's Parent Support Worker project.**







## WONDERS & WORRIES APP, PODCAST, WEBINARS, NEWSLETTERS & HELPLINE

W&W provide a range of methods to support the parents of the children who are enrolled in their programmes. There is a free app that covers topics such as, child development and parenting, illness communication strategies, and family resources and activities. They deliver regular online WonderChats webinars themed around improving communication, coping or connection within a family and send out quarterly newsletters with updates on family events.

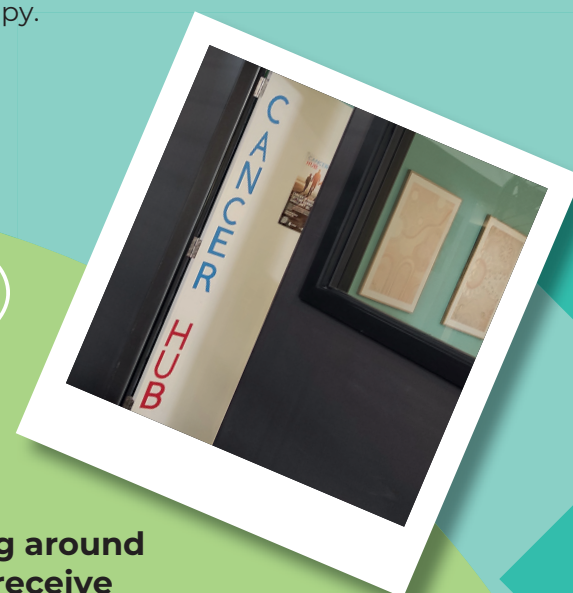
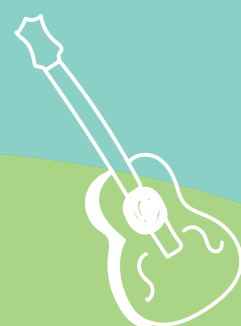
In 2021, W&W started a helpline run by CLSs. Parents can contact at any time via email or phone during specified times of the day. For some parents this brief therapeutic interaction is enough.

W&W also broadcast a podcast that was initially developed to help parents feel less alone when receiving treatment during Covid isolation. It was a privilege to be interviewed (Season 6, Episode #54) (22) during my research and to share my story with their listeners.



## CANCER HUB PARENT COUNSELLING

Parents referred to the Cancer Hub can access six sessions of therapy, but most only attend two sessions. Their data shows that parents seek support at points of crisis, typically at diagnosis, and end of treatment. As a consequence, the Cancer Hub recognises that a 'helpline' type of support, similar to W&W, would be more beneficial to parents and more cost effective than six weeks of therapy.



**It is clear that brief interventional support given at points of crisis is what many parents need. It might be to validate their parenting skills or help with problem solving around a child's behaviour. The number of emails I receive each week from parents asking for advice is increasing and usually my reply with a small amount of guidance, resources or signposting is enough.**

**A more detailed exploration around the reasons why parents are reluctant to seek help is needed. It might be that they are in denial about what is happening, or distrust outside support, or feel guilty about not being a perfect parent.**

## Theme 3: Supporting families impacted by cancer

### WONDERS & WORRIES FAMILY SESSIONS

The advanced cancer curriculum has an additional seventh session for the whole family, not just the child. It is where families can connect, communicate with one another and do legacy activities together in the safe space held by the CLS. There is an important flexibility in W&W programming that allows the child to have a limitless number of family sessions, until they age out at 18 years of age. This gives the families the best level of care and tailors the support to the needs of the individual child.

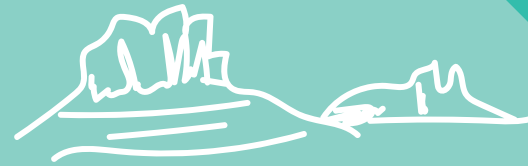
I was honoured to sit in and participate in a game of Jenga with one family. The nine-year-old boy had been seeing the CLS for a few years, and finally the dad, who was dying, agreed to come and be part of a session. Taking it in turns, we pulled out a Jenga piece and answered a question about feelings.

I found it hard to observe the boy's need for his dad's approval and to listen to his dad's criticism of his son. Again, I was astounded by the CLS who skilfully balanced everyone's needs, whilst managing to support the child and help them regain some control over the session.



**There is a fear that teaching children skills, in isolation from their parents, might lead to a failure in them practising these skills at home and within their family life. There is equally a fear that teaching parents new tools and strategies in isolation might also invite failure, as to embed them at home might feel like a heavy impossible task. Perhaps the most comprehensive and effective support for a family affected by parental cancer would be working with the whole family - children and parents learning together, from one another and being accountable for each other when embedding new tools or skills into family life.**





## CAMP QUALITY FAMILY EXPERIENCES AND W&W FAMILY FUN DAYS

Historically, Camp Quality offered children and teens camp experiences where they would spend time with peers. Since Covid-19, they changed their strategy after recognising that a child's primary need was no longer to get away from their family when their parent is sick, but to have meaningful moments with them. Camp Quality introduced Family Experiences (23). These experiences range from a family camping weekend, a day trip or a fun event such as a sports game. The primary focus is for the family to be a family again away from the stresses of cancer. Peer-to-peer support is a by-product as families come together.

These family experiences are also seen as an entry point for families to access more support from the charity, for example, children will have more confidence and will more likely attend camp without their parents.

The aim of family fun days organised by W&W is to get families together in a social setting for peer-to-peer support and to give free access to fun experiences, especially for those who cannot afford them. They also provide a space for staff to check in with the children, particularly if the children had completed the curriculum but do not participate in any offered support groups.



**Across the UK there are various small charities and trusts offering fun experiences to families impacted by cancer. For example, The Osborne Trust offer families days out, and some Maggie's cancer support centres put on Family Days where families come together to engage in activities.**

**WOLO Foundation (24) have a weekend festival each year and Shine Cancer Support have an annual camp (not exclusive to families). However, like most support in the UK, it is dependent on where the family lives and whether families, or healthcare professionals, know these charities or events exist. A possible way to begin to address this would be for regular Family Days to be run at every twenty-four Maggie's Centres located across the UK.**



## Theme 4: Coaching as a therapeutic intervention

### WONDER & WORRIES WONDERWORKS

W&W's new initiative enables families to empower themselves through using a physical box of therapeutic tools at home. These tools focus on improving a family's communication, coping skills and connection opportunities. An interesting piece of this project is that families have an opportunity to engage with a CLS during online coaching sessions as they progress through the tools in a self-paced manner.

At the moment, families access these Wonderwork (25) boxes via their healthcare providers who buy them in to give to their patients. It is a pilot project so it will be fascinating to compare the outcomes of this project to their six-week curriculum intervention.



### COMPASS PROGRAM

Compass is an online program designed to support parents navigating parenthood after their child or young person has been diagnosed with cancer (26). It is a collaboration pilot project between Canteen, Camp Quality and Red Kite and developed in response to families' feedback. It focuses on five key areas:

- 1 Adjusting to changes in family life
- 2 Managing the parents' emotions
- 3 Responding to children's big emotions
- 4 Responding to children's challenging behaviours
- 5 Strengthening family relationships.

The self-paced program features guided activities, real stories from parents sharing their experiences, as well as opportunities to join group coaching sessions after each activity. It is a similar model to Wonderworks above, i.e. an activity followed by a coaching session.





For the last two years we at Fruit Fly Collective have been running our online Parenting with Cancer coaching programme (27). Our data shows that parents significantly improved their confidence in their parental role, their mental wellbeing and many aspects of parenting. At the end of the programme, parents reported wanting an 'advanced' programme. We could perhaps we could introduce a Wonderwork/Compass model, i.e. parents completing a therapeutic activity with their children and then attending a coaching group. It would help to continue the peer-to-peer support that parents found so empowering and would reduce the concern that working with parents alone is not as effective as working with a family. Each activity could embed the learning from the coaching programme into their family life.

I'm eager to learn from both the Wonderworks and Compass pilots. The W&W team has recently reported that the coaching part has not been utilised as much as they thought. It is possible that the word 'coaching' may be alien to some parents, so changing the language in the marketing material may help.

We have previously partnered with Loha Community Health (28), which has developed a digital intervention for young people's mental health. They have a very similar model to the Compass project and have also reported low numbers of parents responding to the coaching element.

The behaviour of parents not engaging with coaching could be because if an intervention is self-paced without a specific date, time or activity to connect with, parents are less likely to commit. Their lives are already undergoing levels of change, trauma and additional stress, so they may not have the capacity to engage in an ad hoc way. This behaviour may also explain why parents in Canteen's community did not engage with a peer-to-peer forum they specifically asked to be set up.



## Theme 5: Cancer education for children

### CAMP QUALITY CANCER EDUCATION PUPPET SHOW

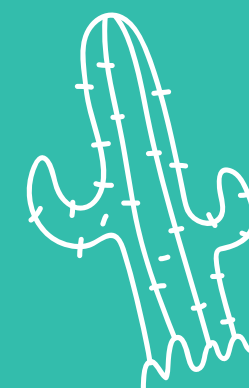
Camp Quality offers a Cancer Education programme (29) for primary school aged children. It is a carefully scripted age-appropriate puppet show that uses trained puppeteers who learn basic cancer education in order to answer children's questions. There are two different puppet shows for different aged audiences (5-7 and 7-11 years) and they focus on what cancer is, empathy and how to be a good friend. Teachers within the schools receive resources from Camp Quality that are aligned with the curriculum.

The outcomes are incredible, showing a reduction in bullying, absenteeism and the need for mental health support. In 2023, Camp Quality went into 518 schools.



After a demand from parents and daycare providers, scripts for nursery children aged between 3 and 5 years are currently being developed, and a film targeting 11-15-year-olds is also being made. This fictionalised film is based on true stories and focuses on five perspectives: the child, the parents, the siblings, the grandparents and the school.

It began 30 years ago, after the founder of Camp Quality overheard stories from children at camp about how they were being bullied at school and felt very isolated. Using The Muppets as inspiration the cancer education programme was developed.







## CAMP QUALITY APP

Kid's Guide to Cancer app (30) is an excellent resource that I have been recommending to every parent and healthcare professional for many years. It is an easy to digest, non-frightening way for children (and their families) to understand what cancer is, how it is treated and what side-effects may occur. Camp Quality have now translated this into four different languages relevant for their communities and their impact data for 2023 shows it has been downloaded 1,538 times.

**Learning about Camp Quality's cancer education programme really excited me as there are such parallels with Fruit Fly Collective's primary education cancer education programme that we delivered to over 1,000 children in Southeast London in 2017-2018. Children are very curious about cancer and want to learn about the disease, even those who are affected by it within their families and communities. We saw the positive impact using the whole school approach (all staff were invited to a training session before we delivered the children's workshops) as adults became less fearful talking about cancer, and it became much more of a normalised subject. It is frustrating to know that our shared learning has not changed the agenda of cancer education in schools. The number of emails we receive from teachers increases, as do their concerns about their affected students.**

Camp Quality recognises the importance of providing cancer education and are campaigning for all schools to access it. Their data shows that the economic impact of provisions for children's mental health is significantly larger than delivering educational puppet shows in schools. They calculated that the total social return on investment of the primary school cancer education programme is 502%. Camp Quality are currently lobbying for their cancer education programme to become part of the curriculum as every child is going to be impacted by cancer at some point of their lives. We should be doing this in the UK.



## Theme 6: Education and training for professionals

### WONDERS & WORRIES 'BECOMING A REGISTERED PROVIDER'

In order to grow and reach as many affected families as possible, both nationally and internationally, W&W license their six-week intervention curriculum allowing anyone with qualifications in mental health to become a 'Registered Provider'. It is an opportunity to learn how to deliver and support children who have a parent diagnosed with a serious illness. There is a comprehensive provision for registered providers, with live coaching, updated resources and training, as well as an annual conference that bring all of the providers together to share best practice.

## WONDERS & WORRIES CONTINUING EDUCATION PROGRAM

W&W has extensive Continuing Education program. There are recorded webinars freely available online at no cost, or online fee-paying courses. The wide breadth of topics shows a dedication to improve professionals' confidence, skills and knowledge in supporting children affected by parental illness.



### Continuing Education program topics include:

- How to help children and teenagers understand and navigate parental illness or injury
- Anticipatory grief: supporting children of adult patients
- How to help children and teenagers understand and navigate parental illness or injury
- Honouring patients and families through family centred culturally and linguistically competent care
- How to help children and teens prepare for and cope with loss
- Play-based diagnosis education

## WONDERS & WORRIES APP, AND NEWSLETTER



W&W reach out to their professional community in multiple ways. There is a free app (31) that explores nuanced topics, such as faith and bereavement, and how to encourage a reluctant parent to talk to their children about their disease. Termly newsletters provide professionals with updated information on their current programmes or events for families, as well as training they are delivering.





We know in the UK that cancer healthcare professionals report feeling a lack of confidence in supporting their patients' concerns around their children. They have no formal training, resources are limited, and they are deeply concerned about doing more harm than good when advising their patients. There is a demand for the free online webinars for professionals that we run which provide the basic training in supporting patients with parental responsibilities.

However, we struggle with funding these training sessions as public grant bodies, who fund our work, expect this training to be covered by the NHS. Navigating who to contact and how to access NHS funding is challenging.

## Theme 7: Outreach with stakeholders



Camp Quality and Red Kite have representatives who are embedded part time at certain hospitals so families can immediately be referred to their services. Data from Camp Quality shows that contacting a parent after their diagnosis, within the hospital setting, gives them the highest number of referrals. It is surprising that some hospitals do not take the opportunity to have a representative in their clinical space even though it is no cost to them.

W&W create small packs for families containing information about their services and a little gift for the child. These packs are given to nurses, social workers or case managers working in local hospitals, who give them out to patients identified as parents. The parent's details are taken by the hospital staff so that a CLS can contact them in approximately a week's time. The space between referral and contact allows parents to process their diagnosis and be less emotionally overwhelmed so that they can understand how W&W can help.

'We treat the disease, but f\*\*\* them up. We need you at Camp Quality to help them live their lives.' A consultant oncologist, working in a hospital where Camp Quality representatives are embedded.

There are two important takeaways. Firstly, a timely approach is needed for parents to be given information about support services. Secondly, if a member of staff from the support charity is physically present during this critical time, a family is more likely to receive support. This is the exact opposite of what commonly happens in UK cancer clinics - overwhelmed parents at their initial consultation being handed a charity leaflet alongside multiple sheets of information about their treatment.



## Theme 8: Equity

I wanted to understand the challenges and the successes these charities had in engaging with culturally and linguistically diverse communities. I found that staff from either marginalised communities or who are bilingual are employed to help break language and cultural barriers. The Spanish speaking CLSs at W&W, and Aboriginal CNs at the Cancer Hub have been hugely successful in creating an inclusive service. For example, the Cancer Hub was contacted by an Aboriginal grandma because her granddaughter had stopped attending her treatment appointments. The Aboriginal CN was able to go to the family home (a practice they do not normally do), build trust with the family and eventually encourage the granddaughter to go back to hospital to receive her treatment, hence significantly changing the outcome of a young person with cancer.

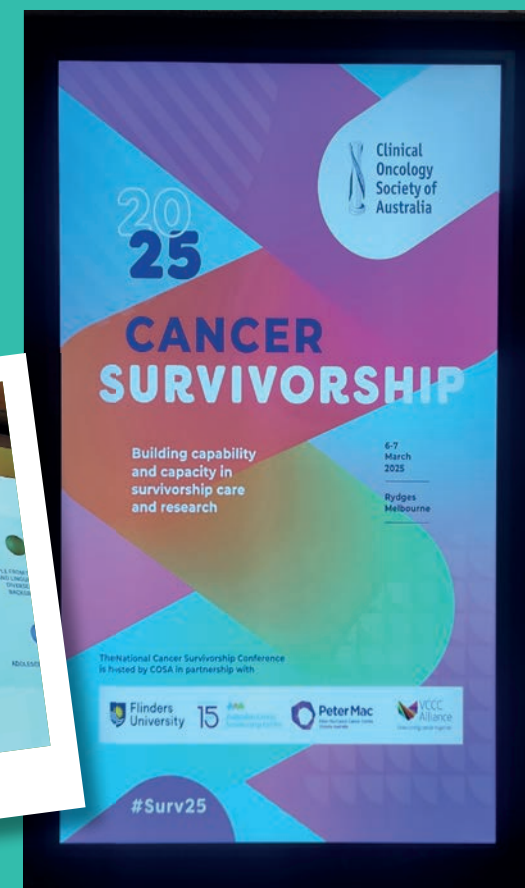
The obvious challenge is the lack of diversity within the professional field. For example, it takes a long time, and therefore money, to train as a CLS, an option only available to those who have financial resources. Spanish speaking staff are in the minority which opens gaps in the support offered to Spanish speaking families.

Translating information booklets, apps, or webinars into native or relevant languages is a common practice. Camp Quality outcome report shows that their app 'A Kid's Guide to Cancer' has been downloaded 505 times in Chinese Traditional language, 810 in Chinese Simplified, 1,260 in Arabic and 985 in Hindi.

The financial stress of paying for treatment, together with the rising costs of living, has a huge significant impact on a family. The conference on Cancer Survivorship in Melbourne, Australia, heavily focused on 'financial toxicity' as many people have to travel vast distances or relocate to receive treatment.

In order to help families on low incomes, all the charities in both the USA and Australia I visited provide food and petrol/gas vouchers.

To reduce travel and logistics costs, many of the support programmes have been digitally adapted (a process fast forwarded by the Covid-19 pandemic). CLSs needed to become very creative to ensure they were able to hold safe therapeutic space with children online. For example, for the pumpkin smash activity, CLSs sent pumpkins to each teen house prior to the online session (an adult must be at home for the smashing part!)





The statistics around marginalised communities accessing support in Australia and the USA feels very familiar to the UK (32). For example, only 8% of the Aboriginal communities are supported by the Cancer Hub, even though these communities are disproportionately affected by cancer.

We must acknowledge the cultural barrier of seeking and accepting support from charities predominately run by white middle-class people. We need to meet marginalised communities where they are to 'reach in' rather than to expect them to reach out. We often think that by translating our information into different languages we have ticked the inclusivity box, but we know that there are many reasons behind the lack of engagement. It might simply be that the cultural norm is to rely on family and community and not outsiders, or more complex reasons, such as the lack of trust from communities who have been treated badly, exist with historical trauma, or racism.

Researching whether parents from culturally and linguistically diverse backgrounds want support is the first step. The second would be to ask what does this support look like. The only way to know is to work together, co-developing and co-designing services in partnership. We also need to be more flexible in how we approach and deliver, just like the example of the Aboriginal CN who attended home visits.

In the UK, even though parents do not have to pay for their cancer treatment, increases in living costs is a key challenge, especially for parents who can no longer work and/or need to travel for treatment. Unfortunately Macmillan, a charity who since its inception, no longer offers grants to individuals to cover some living costs. I'm unsure of any other charities in the UK that offer food or fuel vouchers. The lack of these grants will surely have a dire impact on the mental and physical health of affected families.

The benefits of adapting support programmes for online delivery with lower costs and wider access is even more apparent in the current economic climate.

During my research I was invited to take tours around Texas Oncology in Austin, University Central Hospital in San Antonio, Manly's Adolescent and Young Adult's Hospice in Sydney and Canberra's Regional Cancer Centre. Exploring cancer care within different countries highlights the complexity of healthcare systems. The financial impact of having cancer is huge and listening to stories of people who are having to find thousands of pounds for treatment, when in the UK it is free, it is difficult to understand the added damage this causes a family.

It was interesting to attend the conference in Australia on Cancer Survivorship as it highlighted the differences in research that countries focus on. For example, there was not one poster, study or mention of parenting whilst living with cancer. Research focused on the financial burden of having cancer, and interestingly, the positive outcomes of empowering people with lived experience to be part of the research, development and design of new initiatives.

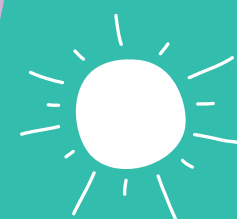


## Theme 9: Empowering the community



Inviting communities to become involved in decision-making and service development is key to creating programmes that are relevant. Camp Quality has a parent group who help guide the organisation, as well as a 'Children's Voices' group that provide important feedback on whether their needs are being met. Canteen have a young person's leadership and training scheme that ensures they are involved in promoting and leading the charity as well as being integral to its growth. Parents with lived experience were instrumental in designing the Compass project. Their voices steered the development, and their presence, in the form of short videos on the online platform, creates a community of shared experiences that is nurturing for parents about to start the programme.

W&W invite teenagers, who are not using their services to become part of a teen council which runs every year. Around 30 teens pay a small fee (revenue for W&W) and for six months they get an understanding on how to run a non-profit and how to plan a fundraising event. This is a remarkable way to include the community who are currently not needing support from W&W but are aware of its existence should they ever need it in the future.



### A DOG FASHOW SHOW



By empowering their communities, the charities not only built relevant and meaningful support services, but also promoted their services and created volunteer bases. This happens in the UK but there is one gap. The voices of children and young people that face the challenges of day-to-day living with a parent with cancer are missing. We need to invite them to be part of the service development to ensure that they are getting effective support at the right time and in the right format.

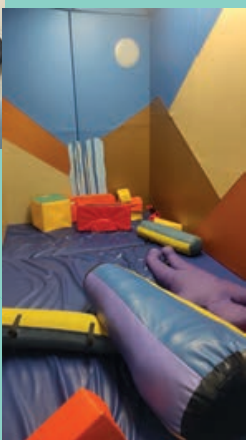
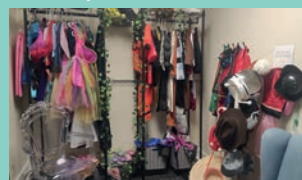






## Theme 10: Collaborations

Across the US, there are quite a few organisations that support families impacted by cancer; some are national, but most work within their state boundaries. W&W collaborate with many organisations to provide coordinated support for their families. For example I was privileged to meet the teams behind Loss of Life Advocates (33), an organisation that assists a family after a parental death with legal and financial support; Flatwater Foundation (34), a free counselling service for adults affected by cancer; Kessem (35), a national charity that run camps amongst other forms of support; and the Children's Bereavement Centre South Texas (36), one of the most of inspiring beautiful spaces I have ever visited that enables children and families to grieve a family member.



The collaboration between Canteen, Camp Quality and Red Kite, in the form of the Cancer Hub, was a significant move to build a stronger, and more coordinated form of support. Cancer Hub employees are embedded within each of the three charities, ensuring clear communication between them. They also collaborate together in research and pilot projects.

**The USA, Australia and the UK have followed the same trajectory in recognising that collaborations between organisations is key to building a service that is sustainable, stronger and more comprehensive. There is less waste in resources which means new ideas have the space to grow. The 'together is stronger' message and practice from the three collaborating Australian charities also demonstrates the possibilities for single charities to work together. In the UK, it feels we are getting there. Smaller charities and grassroot organisations are more likely to partner together and work less in silo as we recognise that one organisation cannot cover all the non-medical needs of a cancer patient. But the competition for small pockets of funding is not conducive to creating a collaborative culture and there is a lack of understanding of which organisations are out there and what they offer.**

# 5

## KEY FINDINGS



Support for a family impacted by parental cancer needs to be:

- Delivered in different formats (e.g. activity or coaching programmes, digital information, helplines, family experiences) and appropriate for different audiences (children, teens, parent or family)
- Timely, given at these critical points: at diagnosis, end of treatment and when there is a prognosis change
- Easily accessed without complicated referral processes.

Children and teens have a better outcome if they understand their parent's illness and are given coping, communication tools and skills, and have access to peer-to-peer spaces.

At initial diagnosis, if a patient is identified as having a parental role they can be given this timely specialised support but many parents may only want or need a single brief interaction with support services.

A more comprehensive system of support can be given to families if charities are coordinated, work together and effectively engage with the healthcare provider stakeholders.

Cancer education delivered in all schools has an economic benefit.

Similar to the UK, the third sector float around the medical healthcare system but are never firmly rooted into the care received by patients. If patients get support from charities it is often dependent on whether the stakeholders engage with them.

The same challenges found in the UK, such as supporting culturally and linguistically diverse communities, building partnerships with stakeholders, and sustaining funding streams also exist in the USA and Australia.





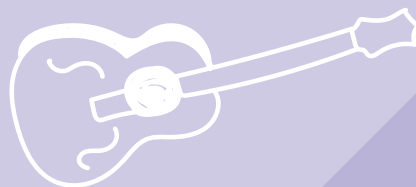
# 6

## RECOMMENDATIONS FOR THE UK



### CHILDREN

- 1 Build support for children impacted by parental cancer by training staff employed in children's mental health services, or in cancer charities, using the W&W 'Becoming a Provider' initiative.
- 2 Develop an online space for the voices of children and young people who have experienced the impact of living with a parent diagnosed with cancer, helping to capture their needs and reducing loneliness in this group.
- 3 Create virtual camps for children using the Camp Quality model to improve mental well-being and reduce feelings of loneliness.
- 4 Reduce the economic impact of offering provisions for children's mental health by including cancer education in schools, from early years through to higher education.



### PARENTS

- 1 Provide a helpline for parents where brief interventional support is given, such as information, signposting, guidance and reflective listening.
- 2 License Fruit Fly Collective's Parenting with Cancer coaching programme, using a similar model to W&W, to expand capacity and support more families.

### FAMILIES

- 1 Create spaces where families can come together for peer-to-peer support to learn about the impact of cancer on navigating family life.
- 2 Develop an online family programme for parents who have completed our Parenting with Cancer coaching whereby each week a family does an activity followed by a group coaching session.
- 3 Deliver online family cancer education workshops to increase understanding about the disease, and its treatments and side-effects, and build empathy within the family.
- 4 Research to increase understanding on what support looks like for families from culturally and linguistically diverse backgrounds.

### HEALTHCARE PROFESSIONALS

- 1 Develop a comprehensive training programme for health and social care professionals on all aspects of parenting with cancer from diagnosis to end of life.
- 2 Embed Parent Champions in hospitals. These champions are trained in the needs of a parent diagnosed with cancer so they can support patients with relevant information, guidance and signposting.



### A DREAM SCENARIO: A FAMILY SUPPORT PATHWAY





# 7 NEW COLLABORATIONS & NEXT STEPS

I am grateful for the openness and enthusiasm I was met with during my research, and that I get to continue working with these charities after my Fellowship has ended. Many ideas were bounced around on how best to collaborate, which projects should start first, and how to share resources.

## SHORT TERM



Co-designing an online Family Cancer Education workshop with W&W to give families a space to learn together what cancer is, how it can be treated, what side-effects can occur and how all this can impact family life.

Research with Canteen around the impact of parental cancer on neurodivergent children, and specific support needed.

Invitation for W&W and Camp Quality to join Fruit Fly Collective's 'Becoming a Surviving Parent' research starting in June 2025.

Presenting Fruit Fly Collective's coaching parents data at the Clinical Oncology Society of Australia (COSA) Cancer Survivorship conference in 2026 (dependent on funding).

Sharing resources, research and data between all organisations.

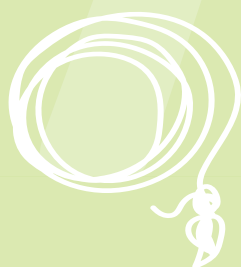
Keynote speaker session for W&W at Fruit Fly Collective's conference in 2026/2027 (dependent on funding).

## LONG TERM

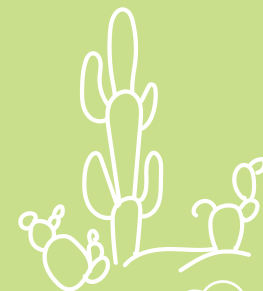
Fruit Fly Collective team members becoming a registered provider of W&W's six-week curriculum to support children impacted by parental cancer.

Potential adoption of Pip (our kit for children with a parent in palliative care) to provide a meaningful link between services that W&W and the Children's Bereavement Centre South Texas provide.

It has also been wonderful to connect W&W in Texas with Camp Quality in Australia who as a result are keen to work together. This cross-pollination proves that the impact of the Churchill Fellowship reaches wider than the UK.



# 8 ACKNOWLEDGEMENTS



To the entire team at Wonders & Worries who showed such generosity, allowing me to shadow them, participate in support groups, family sessions, record a podcast, sit in a teen council meeting and professional learning sessions. Especially to Missi and Meredith, the co-founders of the organisation, who designed a three-week action-packed itinerary for me and gave their time to highlight all parts of their work (and drove me from Austin to San Antonio and Houston). And to Kim, whose insights will always stay with me, including her dream life of living in an RV.

Deanna  
Brent  
Alex  
Michele  
Julie  
Beth  
Adrianna  
Whitney  
2 x Ashleys  
Chris  
Danielle  
Denae  
Francine  
Heike  
Jessica  
Kira  
Leah  
Maria  
Nicole  
Nikki  
Tatiana

To Fiona, Siona, Kit, Xiomara and Tayhla at Canteen. Damian, Caitlyn and Kylie at Camp Quality. Nicole, Dan, Bridgette and Rianna at Red Kite. Kate at the Cancer Hub, and Joanne and Kate from Canberra Cancer Hospital.

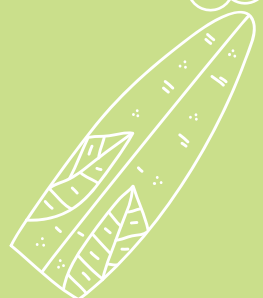
To all the people who took time out to talk to me, share their stories, and show me new experiences.

And finally, to my husband James who supports my ambitions, and to my kids, Thomas and Alex, for always igniting curiosity within me.



The Churchill Fellowship has been the best opportunity I have had in my professional life. It has taught me so much about what is possible and allowed me to reflect on my work and my professional (and personal) journey, an undertaking I generally neglect. It has inspired me to be courageous, take the leap and lay down the foundations of a possibility where every child in the UK gets the support I would have wanted when I was 12.

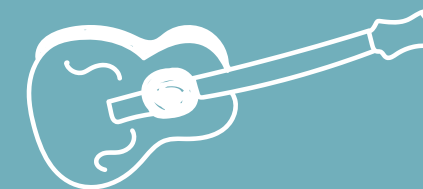
My time spent with these charities was never long enough. There were many occasions, during writing this report, where I wished I asked more questions about a specific area, (it explains the gaps in my understanding and knowledge) but I am so grateful that I can continue to communicate with them, so my learning can continue, and our connections can deepen.





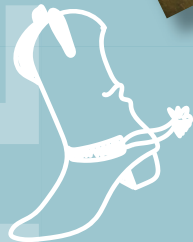
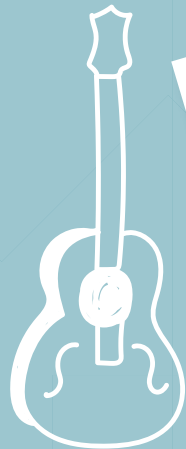


# 9 REFERENCES



- 1) <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age>
- 2) Koh, B., Tan, D.J.H, Ng, C.H., (2023) Patterns in Cancer Incidence Among People Younger Than 50 Years in the US, 2010 to 2019. JAMA Netw Open ;6(8).
- 3) <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview>
- 4) Semple, C.J., McCance, T. (2010) Parents' experience of cancer who have young children: a literature review. Cancer Nurs. Mar-Apr;33(2):110-8.
- 5) Huizinga G.A., Visser A., Zelders-Steyn Y.E., Teule J.A., Reijneveld S., Roodbol P.F. (2011) Psychological impact of having a parent with cancer. Eur. J. Cancer;47:S239-S246.
- 6) Turner, Jane et al. (2009) Enhancing the capacity of oncology nurses to provide supportive care for parents with advanced cancer: Evaluation of an educational intervention. European Journal of Cancer, Vol45,10: 1798-1806.
- 7) <https://www.fruitflycollective.com/>
- 8) <https://ruthstraussfoundation.com>
- 9) <https://hopesupport.org.uk/>
- 10) <https://www.mummysstar.org/>
- 11) <https://theosbornetrust.com/>
- 12) <https://wondersandworries.org/>
- 13) <https://www.canteen.org.au/>
- 14) <https://www.campquality.org.au/>
- 15) <https://www.redkite.org.au/>
- 16) <https://cancerhub.org.au/>
- 17) Phillips, F., Prezio, E. A., Panisch, L. S., & Jones, B. L. (2021). Factors Affecting Outcomes Following a Psychosocial Intervention for Children When a Parent Has Cancer. The Journal of Child Life: Psychosocial Theory and Practice, 2(2).
- 18) <https://www.starlight.org.uk/>
- 19) <https://www.maggies.org/>
- 20) Skrabal, Ross et al. (2023). Cancer patients as parents: implementation of a cross sector service for families with adolescent and young adult children. BMC Health Services Research (2023) 23:472.
- 21) <https://shinecancersupport.org/>
- 22) <https://wondersandworries.org/podcast/season-6-episode-54-fruit-fly-collective/>
- 23) <https://www.campquality.org.au/how-we-help/services-and-programs/family-experiences>
- 24) <https://wolofoundation.org/>
- 25) <https://wondersandworries.org/for-professionals/wonderworks/>
- 26) <https://www.compasscancerparenting.org.au/>
- 27) <https://www.fruitflycollective.com/coaching>
- 28) <https://loha-community.com/>
- 29) <https://www.campquality.org.au/how-we-help/services-and-programs/cancer-education-program/>
- 30) <https://www.campquality.org.au/resources/kids-guide-to-cancer-app/>
- 31) <https://wondersandworries.org/for-professionals/professional-resources/>
- 32) Scott, Emily C.S. et al. (2024) Health inequalities in cancer care: a literature review of pathways to diagnosis in the United Kingdom. eClinicalMedicine, Volume 76, 102-864.
- 33) <https://www.lossoflifeadvocates.com/>
- 34) <https://flatwater.org/>
- 35) <https://www.kesem.org/>
- 36) <https://cbcst.org/>

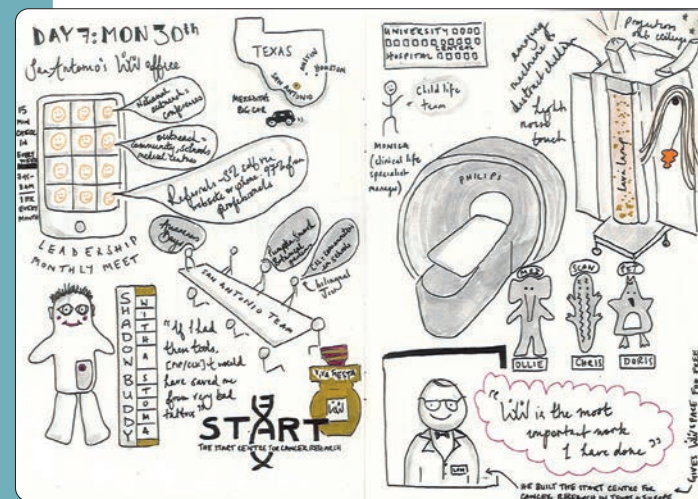
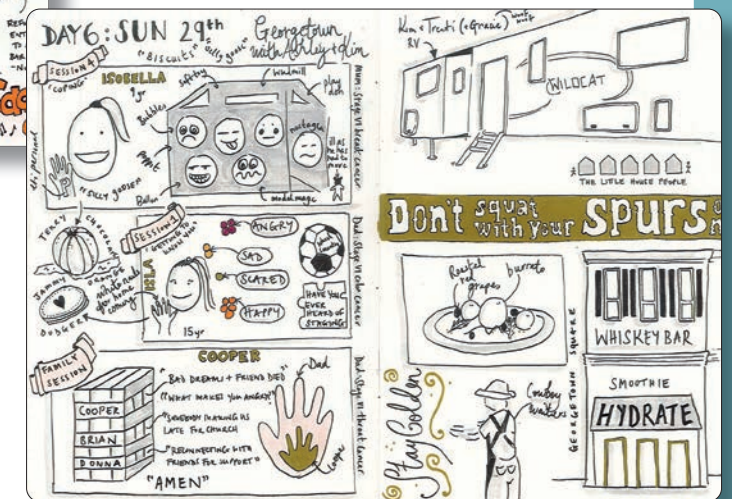
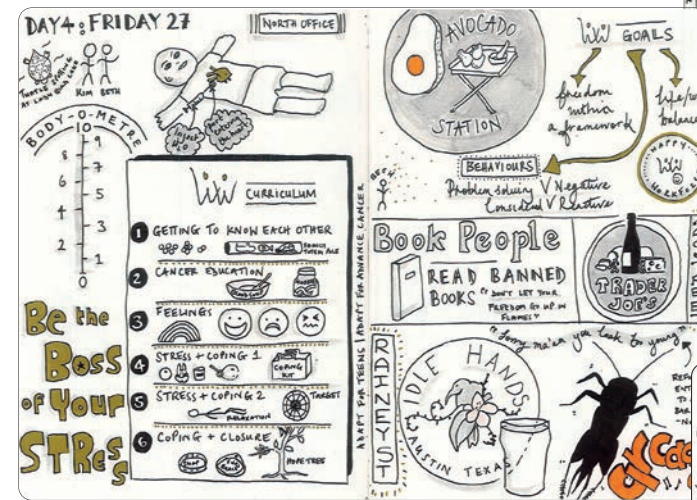
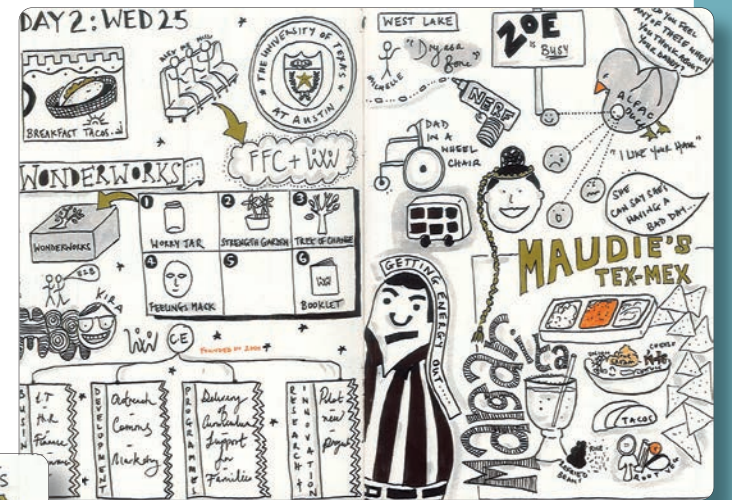
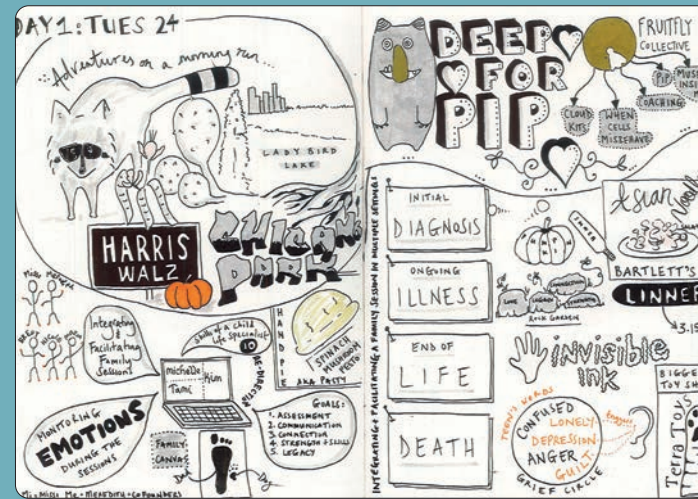
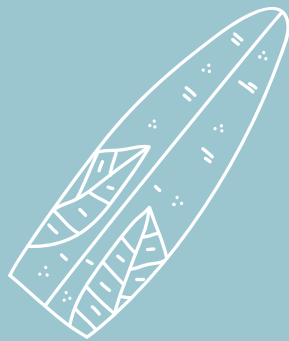






# MY TRAVEL JOURNAL

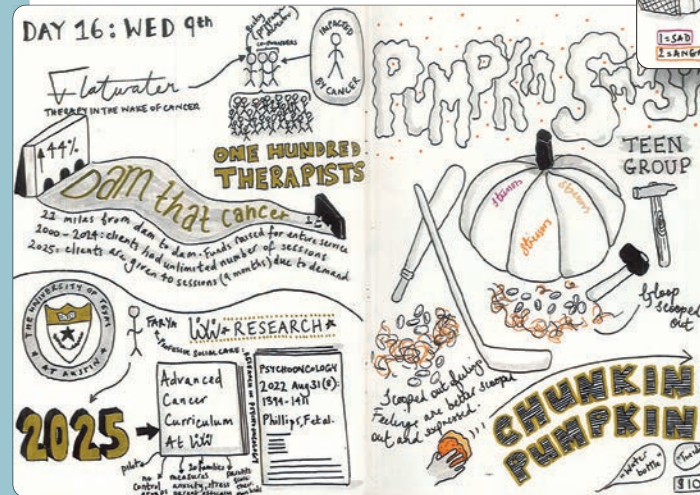
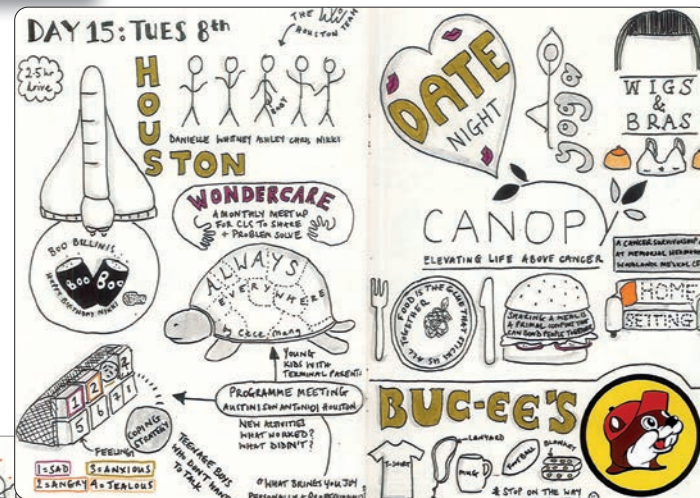
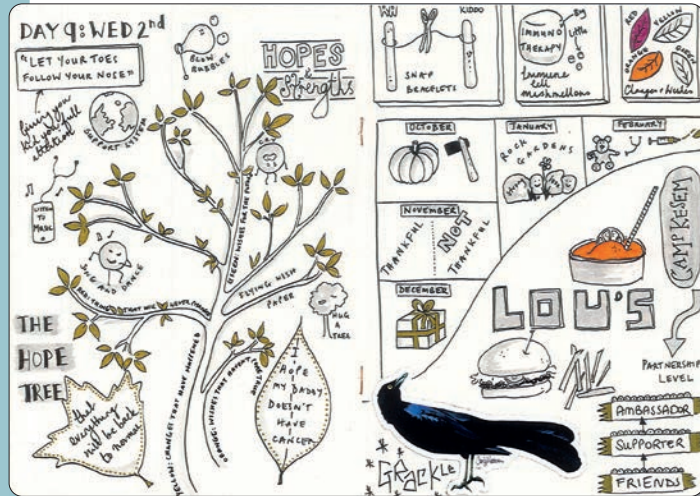
## My travel Journal



# TEXAS



# TEXAS



# AUSTRALIA

