

Oncology Services Group

# Life back in the community after cancer

A guide for families



## The next stage of the journey

**C**ompleting cancer treatment can be both exciting and concerning for families. What you've been through as a family has been really tough; tougher than most people could realise.

Finishing treatment successfully means a chance to go back to your 'old' life and for things as a family to return to 'normal'; although this 'normal' will probably be different to before. Finishing treatment means the chance to be together as a family again without having to visit the hospital so much. But finishing treatment can be a time of worry.

For example, there is reduced contact with your medical teams and less monitoring. It is normal to be concerned about whether the cancer will return but it's important not to let this worry interfere with day-to-day life. If you do have ongoing concerns, talk to your regional health team.

Finishing treatment is a time to celebrate. You can look back on how you managed such a difficult time in your lives; how brave and strong you have all been to have survived! Hopefully, the toughest days are behind you. Now you can get used to the next stage of your cancer experience as 'cancer survivors'.

It is OK to leave the cancer behind and get on with life. But if leaving the cancer behind feels tricky, there are tips and people to support you as you try to work out what comes next.

This booklet covers those tips, support people and some of the ongoing needs your child may have following cancer treatment. Most survivors of cancer and their families go on to really enjoy life, even though they may still have a few after treatment complications or worries. It is important to remember at all times that you are the expert on your child and your family. This is just a small book of suggestions.

## Life back at home

### Medical support after treatment

The end of treatment does not mean people in the hospital stop caring about you. The Oncology Services Group (OSG) team will continue to care about your child and family. However, in order for you to go home and feel safe and supported, we will move your care to your local area.

If you live in a regional town or city, the OSG team will contact your paediatrician at home and will link you with the paediatric oncology team there. We will have a video conference with this team before you are discharged home. Your family will have a regional case manager who will coordinate all of your care and appointments. The regional case manager is a good person to contact if you have any concerns about the effects of your child's oncology treatment. This team will take very good care of you and can also link you back to your consultant and the OSG team if there are any major concerns. If you have to visit Brisbane again, the regional case manager can help organise and prepare you for this.

For families who live within the Brisbane area, the OSG will contact your local general practitioner (GP) or paediatrician so they can manage your child's general medical needs. You can still contact your OSG clinical nurse consultant if you have concerns about the effects of your child's oncology treatment.

Your child and your family have been through a lot — physically and emotionally — so there may still be some recovering to do. Side effects of treatment, chemotherapy and radiotherapy can mean it may take several months before your child has the same level of energy, skills and fun as before; however there are many ways to manage the effects of treatment.



### Returning to normal family routines

Often, family routines and activities have been interrupted by cancer treatment. The need for one parent to be at hospital with the child who had cancer often means their siblings have been cared for by other family members and things might have been done quite differently while you have been away. This can be a little confusing and frustrating at times.

On completing treatment and returning home, some families can find it difficult to re-establish a family routine or may need a change. It may be that you can not just 'fit' back into your old routine. Things might seem different now. You may need to work at creating a new routine or a 'new feeling of normal'.

#### TIP

It can be useful to sit down as a family and talk about what is different, what needs to happen each day and how this can best be achieved. Setting up a timetable may be really useful at first to be very clear and structured about how you want to do things and when, as well as who is responsible for what. This may mean that you use pictures, timetables or diaries to ensure everyone knows their role. Using pictures and photos also means even the youngest kids can be involved. Usually after a while everyone will get used to the new routine and you will no longer need such strict rules.

Family members can often find it difficult or strange being all together again after such a long time apart. Your child who had cancer might find it difficult to 'share' the parent who was with them during their treatment. Their brothers and sisters may also find it hard, feeling like the child who had cancer is getting 'spoilt' or 'had all the attention'.

**TIP**

Sitting down and having a really open talk about how everyone feels may help. Everyone will have had a very different experience or story of what living with cancer was like for them.

Sometimes extended family members may think that once the cancer treatment is finished, your life will quickly return to the way it was. Family and friends may have good intentions but won't really understand what you have been through. This can be tough.

**TIP**

Take the time to settle back in. It could be helpful to talk to extended family about why things have changed and might not go back to the way they used to be. Be patient with yourself and your family as sometimes recovery for all of you might move slower than you hoped. Sharing this booklet with family and friends might help them understand.

If after a few weeks you are still finding things tough, feel free to ring your regional case manager or clinical nurse consultant. They will be able to help you or refer you to someone in your area who can offer more specialised help and support. Be gentle on yourself — you are still 'normal' and are doing OK.

## Physical changes

**Y**our child may look different because of the type of cancer they have had or the treatments they required. **Chemotherapy and radiation therapy are just two treatments that may affect your child's looks or physical abilities following cancer treatment. Some of these changes may stay around for a long time, and others may go away with time and some help from therapies.**

### Ongoing therapies you may need

To help your child recover from all the treatment and time away, they may need to see allied health staff in the hospital or in your local community. Sometimes your child's care team will make these referrals for you before they are discharged. We will send your child's information to your local health care providers so the staff there will know who you are and what services you may need. Outlined below are some of the different services that allied health staff may be able to offer you at home.

### Physiotherapy

Physiotherapy can play an ongoing part in helping your child cope with life after cancer. It helps with all parts of the body and can help your child get back to running, jumping, balancing, breathing and growing like all the other kids of their age.

It is likely and normal for your child to be tired after cancer treatment. They may have lost strength in their muscles and not be able to do things the way they used to. You may notice they struggle to keep up with siblings or friends. They may get puffed easily or have sore joints even after playing for a short time. Returning to normal activities like sport, playing and running around can be hard for some kids but usually with practice and time they do catch up again.

#### TIP

Your child's return to playing and running around will be slow. Physiotherapists suggest starting at one to two minutes a day, then slowly increasing this to 15 minutes. Going for a walk or swim is a great start and the whole family can join in. Stretch and warm up and down together so muscles don't get too sore.



Your child's body may not be used to running and playing again. So for the next couple of days it will be normal for them to say their muscles are sore or tired. If they seem to be in a lot of pain or you are concerned, ring your local health team.

#### TIP

Watch your child closely and stop them if they become puffed, feel really tired or if they have joint pain, dizziness or light-headedness, or any other pain. If any of these symptoms continue after resting, ring your GP, paediatrician, clinical nurse consultant, or regional case manager.

### Dietetics

A dietitian may have an ongoing role in helping your child to eat and grow well following their cancer treatment. Sometimes cancer treatment might make your child not want to eat or make them a fussy eater. Some side effects like poor appetite (not feeling hungry) and taste changes may last for weeks or even months. A diet high in protein and calories (full cream dairy products, meats, eggs, lentils and legumes, and added fats) is really important to make sure your child grows normally.

Try not to force food on your child. If they start to feel bad about food, this can make things worse and stop them wanting to eat even after the cancer treatment symptoms have gone away. For most kids, their appetite usually returns to normal, but the time this takes varies from one child to another.

Taste changes are common. You may notice your child's food preferences have changed. They may not like their favourite food from before. New foods may

taste good. Some food, usually proteins, may have a metal taste. You may avoid these foods until the metal taste goes away.

If your child is going home on nasogastric or tube feeds you will need ongoing appointments with your local dietitian or Children's Health Queensland dietitian. They will give you advice on weaning off or cutting down nasogastric feeds as your child starts eating normally again. They can explain how to make sure your child is not losing weight and is growing normally. Once your child is eating normally through the mouth and keeping their weight stable, the nasogastric tube can usually be removed. The time this takes depends on each child—it may be weeks, months, or sometimes longer.

Once side effects of treatment finish, a return to a healthy balanced diet is important to help your child's body to grow, heal and function well. The body needs protein (meat, seafood, eggs, etc.), carbohydrates (breads, rice, pasta), fats, vitamins, and minerals. Aim to include a variety of foods from the five food groups every day: fruits, vegetables, dairy products, meats/eggs/legumes, and breads and cereals.

Some children may develop difficult eating behaviours, including fussiness or food refusal. This may be related to the bad experiences they had during their cancer treatment (e.g. nausea, vomiting, mucositis, and taste changes). Your child may connect these bad experiences with food and mealtimes. Some children do not understand that these symptoms are due to their treatment and might believe they are related to eating. As a result, they may develop food aversions—refusing to eat certain foods, tastes or textures (e.g. some children will only eat dry, crunchy foods). Children may also become dependant on their tube feeds. It is important to return to normal family mealtimes and encourage healthy eating behaviours.

#### TIP

Having set meal times, and all eating the same meal as a family at the table will help the return of these routines. Avoid distractions at the table (e.g. phones, pets or games). Talk with your child about different foods (what food group they're in, what they look like, smell like and taste like), read books about food, play games with pretend food, and involve your child in food shopping and cooking.

Avoid giving your child the same foods over and over, as this can cause 'food jaggings'. This is when your child becomes stuck on eating a small number of foods over and over and then when they get sick of eating these foods, they don't want to eat anything at all. This makes eating even more difficult.

#### TIP

Offer a wide range of foods from all the different food groups, and avoid giving your child a particular food more than once every two days. If there is any ongoing fussiness or refusal around different foods, please contact your regional case manager or clinical nurse consultant who will contact the local dietetics department.

### Equipment needs

If your child has feeding or swallowing difficulties, you may require specialised feeding equipment. This will be provided by your local speech pathologist. If your child is going home on nasogastric feeds, any equipment you require will be arranged by the dietitian.

If your child has ongoing physical issues, you may require specialised mobility equipment or home modifications for your return home. Home assessments can be arranged as needed by your occupational therapist and physiotherapist.

## Social and emotional needs

**M**ost families cannot wait until 'life after cancer' to begin. But when that time does come some people find it stressful and emotional and they are not sure why.

### Your own emotions

Some families describe feeling overwhelmed and distressed. Some talk of being totally exhausted both physically and emotionally when they return home following treatment. Try not to worry: this is normal. Families tell us that they feel this way because when they were on treatment, it felt like they were 'fighting' the cancer or helping to 'keep it away' and without the treatment they feel really scared it's going to come back.

#### TIP

Go gently on yourself. Give yourself time to settle back into home. Talk to your family and to people you trust about your feelings. Talk with the staff at the OSG and your local home team about your fears — they may be able to give you some facts about how to know when kids are well or when to go and see a doctor. Remember that these fears are frightening but normal. Keep asking your local team to provide practical support and help you identify healthy coping strategies.

### Answering tough questions

One of the hardest questions to answer after cancer and treatment is: Are they cured? This may be especially tough if it's your child who is asking. It is important to answer their questions honestly. Let them know that the cancer is no longer growing and assure them you will keep having check-ups and visits to keep an eye on things. Let them know that they would not have been allowed to stop treatment and go home if the doctor was not happy that they were doing really well. Try to also focus on what sort of things they may now be able to do if the cancer is no longer in their body such as playing, school, art and sport.



### Getting help

If you feel your child or any member of the family is having difficulty getting back into normal everyday life, or if your child or family are experiencing high levels of distress or anxiety for more than a couple of weeks when you get home, contact your regional case manager or clinical nurse consultant who will refer you to social work or other supports in your local area.

### Behaviour management

Often when children are having active cancer treatment, parents change what they expect from their sick child's behaviour. Maybe you let them have different sleep times, eat whenever they were hungry or even understood if they swore or got cranky. Often parents do this because they understand that their child is tired, stressed, anxious, sick of being sick, sick of being touched, etc. Parents also say they too are simply too tired, too sad, missing their other children and partners/life, or feeling too guilty to be strong with their child's behaviour.

Finishing treatment and returning back home is what everyone has been waiting for, but kids can continue to have some challenging behaviours when they get home. It is unlikely that everything will just easily go back to normal in terms of behaviour.

You may need to consider the following to assist all children in the family:

- Re-establish a daily routine. When you were in hospital every day, it may have seemed that you had no routine and that every day was different. Actually, there often was a bit of a routine you may not have even been aware of, especially around sleep and mealtimes. Your child may need some help and suggestions to re-establish his/her normal daily routines. We know that kids often do best when they have a routine and some boundaries so while this may take a bit of effort at first, it will really help your child and the family in the long run. When starting a new routine, you sometimes need to be quite strict and structured. If your child is only young, try using picture cards or photos on the wall to explain what will happen each day. Use a clock to represent roughly what time certain things happen like meals, play, TV and sleep.
- Re-establish some basic ground rules. Basic ground rules may include using manners, having a set bedtime or identifying certain foods that must be eaten each day. It sometimes helps to only re-introduce a few rules at a time.
- Be consistent. All carers should agree on what the rules are and the consequences if children do not follow the rules. It also means that you often have to do the same things over and over or have the same response each time until your child or children get used to the new system.

- Positive reinforcement. Always start with acknowledging and praising your child for the things that they have done right or well.
- Be clear. When rules aren't followed, give your child clear information on what they have done incorrectly and what you expect instead. Also be clear on the consequences of not following the rules.
- Recognise and reward good behaviour. Kids usually respond better to being rewarded or praised for behaviour. So rather than only pointing out the bad things that happen, praise and reward your child when they remember the routine. Keep reminding the kids that everyone has had a tough time and there have been a lot of changes but its time to start enjoying some family time again. Rewards can be simple and free. For example, if everyone goes to bed on time with no fuss three nights in a row, then you will have a 'family movie night' at home.

If you have ongoing challenges with helping your child change their behaviour, contact your regional case manager or clinical nurse consultant and ask for help or a referral elsewhere. Most community child health centres offer a range of parenting support programs, such as positive parenting programs, which can be useful to help parents manage children's behaviour.



## Back to school

**T**he return to school is another important milestone after completing cancer treatment. At first, going back to school may be more about catching up with friends and being part of a group again rather than about learning. It's important for parents to establish a strong relationship with their child's teacher or teachers to assist their child's transition back into the classroom.

Staff from the hospital school may liaise with your child's school to support this change. You can talk to the teacher about this before you go home. The regional case manager or clinical nurse consultant will also be able to assist in liaising and giving education to your child's school.

### Fatigue management

Fatigue means feeling really tired, worn out, and finding it hard to be bothered. When cancer treatment finishes both physical and mental fatigue is very common for kids and their parents. When fatigued, a child will have difficulties concentrating for lengthy periods of time and is likely to tire during a full school day.

#### TIP

Carefully watch how your child goes when they return to school. We recommend that children make a slow return to school, maybe only going for a few hours at first and then gradually staying longer until they can cope with a full day.

Your child's teacher may be unsure as to how they can best help your son or daughter after treatment for cancer. Talk to your regional case manager or clinical nurse consultant about this. CanTeen, RedKite and several other children's cancer services may also be able to help at this time.



### Coping with changes in physical appearance

Children undergoing cancer treatment may experience a range of physical changes to their appearance, with hair loss often the first. Changes in appearance can have an effect on how children feel about themselves and their confidence and how easy it is to return to school and other activities. Support from you and their friends is important.

#### TIP

Try to make sure your child has at least one friend who can be around as a 'buddy' on those first days back at school.

If settling in is proving to be hard, encourage your child to spend time with a special and loyal friend at the weekend.

Parents should act immediately if they have any concerns about how their child is settling back into school or that their child might be feeling 'left out'. You can help your child through this period by:

- Reminding them they are still special and that they are much loved.
- Talking about how all people are often a bit 'different' in their own way and that is okay.
- Reminding them that even though their looks may have changed, inside they are still the same person they always were who likes football/jokes/music/the colour pink etc.
- Reminding your child how much courage and strength they had during their cancer treatment.
- Listening to them and seeking further help if you need it from school, your friends or your local oncology team.

## Coping with changes in physical abilities

Some children have to cope with changes in their physical abilities and what they can do following cancer treatment. Some of these physical changes are because of the type of cancer your child had. Others are because of the health effects of treatment and the chemotherapy or radiation therapy your child may have received.

### TIP

Talk with your teacher about the need for extra drinks and snacks in the classroom, the ability to wear a bandana, cap or hat at all times due to concerns about hair loss (self-consciousness or sunburn), and the importance of needing to be able to rest. In high school, it is also important to ask the teachers to organise greater flexibility when your child has to go to the toilet or change classrooms particularly if there are changes in your child's walking and movement.

The teacher, particularly the physical education teacher, needs to be aware of any specific physical changes your child may be experiencing and the need to watch for issues while participating in physical education classes or any sport. They should encourage a slow return to normal activities, or allow your child to be involved in a non-physical way until they are able to cope with more activity. If any physical concerns arise regarding your child's participation, these should be reported to your regional team or clinical nurse consultant.

## Equipment needs

Your child may need special equipment before returning to school. School visits for assessment can be arranged as needed by your occupational therapist and physiotherapist in your local region.

## Coping with changes in thinking, learning and communication skills

Changes in thinking, learning and communication abilities can sometimes be seen following cancer treatment. Some of these changes are because of the type of cancer your child had. Others are due to the health effects of treatment and the chemotherapy or radiation therapy your child may have received. For example, your child may take longer to do things, they may have trouble concentrating, following multiple directions, or getting a message across effectively. If you feel your child's ability to think, learn and communicate has been impacted, ask your regional case manager or clinical nurse consultant to refer you to an occupational therapist or speech pathologist in your local area.

## Reconnecting with friends

**C**hildren with cancer often don't get to see their friends, go to school, go to parties or play dates, or participate in sport while they are receiving treatment. When they are back home, it is very important to help your child reconnect with their friends. Your child may be excited about seeing their friends again but they might also be anxious. Listen to their worries and don't minimise or dismiss them.

Here are a few suggestions for helping your child through this time:

- Give your child's friends a ring or talk to their parents about the cancer and what has happened while you have been away. Often others feel a little anxious and want to do the 'right' thing. Giving other people information and facts on what has happened and what you are hoping for now can help everyone act more normally and be more relaxed.
- If the thought of ringing people is too much try sending out an invite for a 'welcome home' lunch, BBQ or morning tea. As part of the invitation, include a note about the cancer, the treatment and your experiences and let others know how important friendships will be in your child's recovery, as well as for mum, dad and siblings too.
- If they're feeling confident enough, contact your child's school and encourage their teacher to do a class project on 'life with cancer' inviting your child to come and be the guest speaker. This can help break the ice if it happens before their return to school.
- If your child is older and it's appropriate, suggest they contact their friends first by email, Facebook or a similar method that's safe but doesn't need an instant face-to-face reply.
- Ask your child to invite one or two close friends to your house for a movie night or lunch as a way to ease everyone back into their friendships.

It is important to remember most children will be fine. It just takes time, patience and sometimes a bit of creativity.



## Return visits to hospital

**R**eturning to hospital after the end of treatment can bring back feelings of fear and worry for both children and their families. There is often anxiety about coming back to the place where stressful conversations and painful procedures may have occurred. These feelings are normal – remember that you can speak to hospital staff about this to get appropriate support.

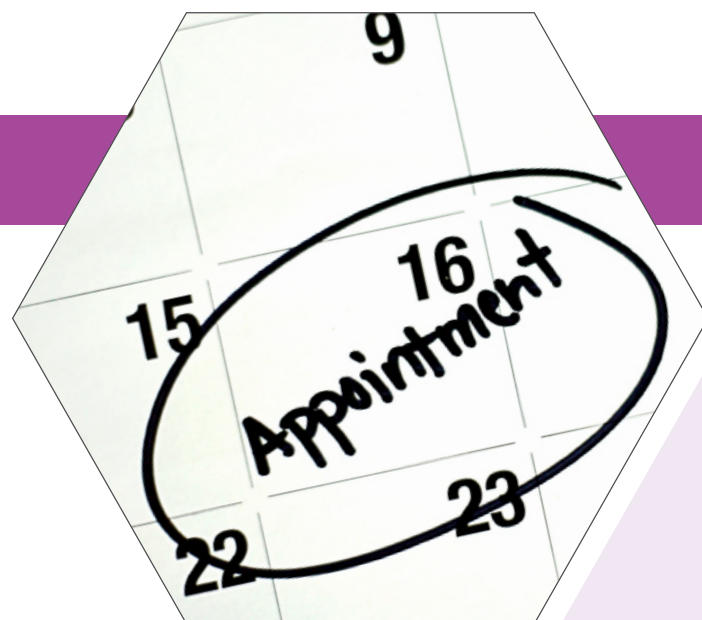
### Preparing for outpatient, after-cancer therapy or long-term follow up clinic visits

Attending clinic appointments once therapy has finished is important to support you and your child through this period of change and adjustment. These outpatient clinic appointments are also used by the hospital staff for routine monitoring. As you and your child continue with these appointments, the period of time between these will grow from weeks to months.

Long-term follow-up is an important part of your child's cancer survival and treatment. Cancer treatments, while necessary and life saving, can sometimes cause difficulty for the longer term health and quality of life of cancer survivors. While not everyone has long-term complications, some of these concerns can first present long after the completion of your child's treatment.

For this reason, we ask that your child continues to attend the hospital or regional clinic from time to time over the coming years, especially as they transition into early adulthood, to monitor for these long term health complications. This is often as simple as a check-up once a year.

As your child reaches adulthood, the OSG team will transition them to adult services for long-term monitoring which may only happen every couple of years.



### Preparing for procedures

A level of worry or anxiety surrounding procedures is normal. This can be particularly for children who have not had any procedures for a while and then have to come back to the hospital. Unfortunately, tests and procedures are the safest way for us to know if your child remains well. We therefore encourage children and parents to develop and keep ongoing coping strategies to help them get through these challenging times.

If it is necessary for your child to complete procedures in your local hospital, your OSG occupational therapist would be happy to communicate with the local team about strategies which may assist your child's coping during these times.

Please note that if your child's procedural anxiety starts to significantly increase or last for longer, additional psychological support may be required. Contact your treating doctor to discuss this.

## Contact us

The OSG team at the Queensland Children's Hospital and regional teams are always interested in your child and family's wellbeing, so please contact us or your local support people if you have any questions or concerns.

### Queensland Children's Hospital oncology nursing and allied health team

#### Clinical nurse consultants

**t** 07 3068 5456  
(ask switch to page your consultant)

#### Dietetics

**t** 07 3068 4746

#### Music therapy

**t** 07 3068 2370

#### Neuropsychology

**t** 07 3068 2950

#### Occupational therapy

**t** 07 3068 2275

#### Pharmacy

**t** 07 3068 1989 (Mon-Fri, 8.30am to 5pm)  
07 3068 1900 (Sat and Sun, 9am to 5pm)

#### Physiotherapy

**t** 07 3068 2240

#### Psychology

**t** 07 3068 5456

#### Social work and welfare

**t** 07 3068 2940

#### Speech pathology

**t** 07 3068 2375

## Support organisations

There are a number of community organisations which can also provide support to your family once treatment is completed. These include:

### BrainChild Foundation

Provides educational and financial support to families with children who have a brain or spinal tumour.

[www.brainchild.org.au](http://www.brainchild.org.au)

### Camp Quality

Provides recreational programs, education programs and family support programs for children living with cancer.

[www.campquality.org.au](http://www.campquality.org.au)

### Cancer Council

Helpline, counselling, education and support for parents and adult family members.

[www.cancerqld.org.au](http://www.cancerqld.org.au)

### CanTeen

Provides support services for young people aged 12 to 24 living with cancer.

[www.canteen.org.au](http://www.canteen.org.au)

### Leukaemia Foundation Queensland

Provides practical care, support and information to families.

[www.lfq.org.au](http://www.lfq.org.au)

### Redkite

Provides support to children, young people and their families through the difficult cancer experience. Services include financial assistance, community-based support via telephone and email counselling and education assistance and scholarships.

[www.redkite.org.au](http://www.redkite.org.au)

### Ronald McDonald House Learning Program

Provides tutoring and teacher support.

[www.learningprogram.rmhc.org.au](http://www.learningprogram.rmhc.org.au)

