

Coming off treatment

A handbook for parents

Coming off treatment

A booklet for parents

You are receiving this booklet as your child has, or will soon, finish their cancer treatment.

Now that treatment has ended, you may feel excited about the future. This is possibly the moment you have been waiting for since diagnosis. Completing treatment is often an anticipated and celebrated milestone. Life no longer needs to be planned around chemotherapy schedules and hospital visits.

However, it may be surprising to discover mixed feelings about coming off treatment: there may be unknowns about the future and questions that need answering.

You may be wondering how to put this experience behind you and return to normal life. There is no perfect way. Just as each child's treatment is different, so is the transition back to a 'new normal'—a phrase often used by cancer survivors and their families.

We hope this booklet will answer some of the questions you have at this time and support you and your family's readjustment back to a life without treatment.

Contents

1

Practical issues

What do I do if my child has a fever?	4
When can the line come out?	4
What if my child still has a feeding tube?	4
How long does my child need to take Bactrim?	4
Chicken Pox	5
How often will we have to visit the outpatient clinic?	5
What happens at follow up visits?	5
What about immunisations?	5
What about travel insurance?	5

2

Feelings and emotions

Is it normal to have mixed emotions?	6
How do I deal with the fear of relapse?	6
Emotional fatigue	7

3

Relationships and family

Feeling isolated after treatment	8
Rebuilding relationships	8
Re-establishing the family to a 'new normal'	8
Siblings	9
How do I communicate with my child about their cancer?	9

4

School

Returning to full-time school	10
Has the cancer treatment affected my child's ability to learn?	11

5

Looking to the future

Healthy living following treatment	12
What about fertility?	12
The Long Term Follow-up Program (LTFP)	12

6

Contacts

Useful numbers	13
Useful websites	14
Books	15

Acknowledgement

PICS would like to thank staff at The Royal Children's Hospital and Monash Children's Hospital, as well as the Children's Cancer Centre Parents Advisory Group, for their contributions in developing this booklet.

PICS would also like to acknowledge the work of the wider paediatric oncology community for the ongoing research and work undertaken to support families of children and adolescents coming off treatment, in particular the work of the UK Children's Cancer and Leukaemia Group.

1

Practical issues

What do I do if my child has a fever?

In the first few weeks after treatment your child may still be neutropenic and you will need to call the hospital if they have a fever. You will also need to call the hospital if your child has a fever and they still have a central line. Once the central line has been removed and your child's blood counts return to normal, it is best to contact your GP as the first option if your child has any fever or illness. Your GP will be able to decide whether or not your child needs to go to hospital. At this stage you should be able to start using paracetamol and ibuprofen for fever.

Remember, after treatment has completed, the most likely cause of fever is a normal childhood illness. It is usually helpful for a member of the oncology team to make contact with your GP when coming off treatment.

When can the line come out?

For most children, the line can be removed as soon as end of treatment investigations are completed. If your child has a port this will be performed as a day procedure under an anaesthetic. The removal of an external line (Hickman's) is a procedure that generally occurs within the Oncology Outpatient Department where your child has been receiving their treatment. Speak to your oncologist for more information about the removal of lines.

What if my child still has a feeding tube?

As your child begins to eat more, your dietitian will work closely with you and your child to wean tube feeds. In general, most children wean tube feeds quickly after treatment and the feeding tube can be removed in consultation with your dietitian and oncologist.

How long does my child need to take Bactrim?

Your child will generally have to take Bactrim until their immunity improves which may be for a few months after treatment.

Chicken Pox

You should contact the oncology team promptly for advice if your child comes into contact with Chicken Pox in the first six months after treatment.

How often will we have to visit the outpatient clinic?

Generally, following the end of treatment, your child will have to return to outpatient department on a regular basis for tests and check-ups. This period generally lasts for 2 to 5 years depending on your child's diagnosis. This timeframe is called the surveillance period. During surveillance, if you are a regional family you may be able to see an oncologist in your local area or use telehealth to see your oncologist with your local GP. There are several sites across regional Victoria that conduct paediatric oncology clinics each year. Talk to your oncologist to see if your child is able to access these services.

What happens at the follow up visits?

Your child will receive a general check-up from the oncologist and any tests will be arranged at this time. The type of tests vary according to your child's diagnosis – your oncologist or nurse coordinator will be able to explain what type of tests will be required for your child. Blood counts are also checked until they return to normal. For patients that have been treated for Leukaemia, some lymphomas or had a bone marrow transplant, blood counts may continue to be checked for a longer period.

What about immunisations?

Many children will need to have boosters of their childhood immunisations repeated about six months after treatment has completed. This will depend on what chemotherapy your child has had. Talk to your oncologist about the need for and timing of immunisations. Your child should continue to have the annual influenza vaccine.

What about travel insurance?

After treatment, some families worry about applying for travel insurance for their child. Your social worker can provide you with advice regarding this. The Victorian Cancer Council can also provide support for families seeking insurance advice. See the links section at the end of this booklet for more information.

2

Feelings and emotions

Is it normal to have mixed emotions?

It is usual to experience a wide variety of emotions at the end of treatment, from relief and happiness to anxiety, anger, uncertainty and a fear of the future. Remember these are all typical emotions when coming off treatment. There is simply no right or wrong way to feel.

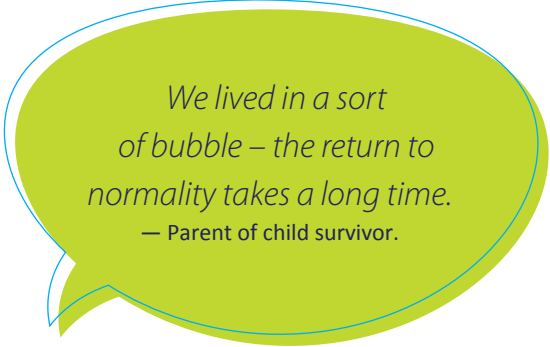
If you are feeling overwhelmed it is important to seek help by talking to someone such as a friend, family member or a professional. Your social worker can assist you to organise counselling in your local area.

How do I deal with the fear of relapse?

It is very common and natural for parents to fear relapse. While your child is on active treatment, there is a sense that everything is being done to beat the disease. When treatment stops, worry about the cancer coming back may increase, particularly when you are waiting for the results of scans or tests. If you are struggling with the fear of relapse remember:

- Most childhood cancers never return
- The chance of relapse gets smaller the longer your child is off treatment
- Your child's treatment was carefully planned – there is no evidence that prolonging the treatment would be of greater benefit
- For many children, there is still hope of a cure even if the disease does come back.

Please contact your oncologist or social worker if you feel you need further support or reassurance during this time.



*We lived in a sort
of bubble – the return to
normality takes a long time.*
— Parent of child survivor.

Emotional fatigue

You may be feeling the emotional and physical drain of parenting a child with cancer. Your energy reserves may now be depleted as you come to terms with this experience. At this stage, some parents feel that they just can't take any more. Some things that have been shown to manage emotional fatigue include:

- A gradually increasing exercise program
- Relaxation techniques such as slow breathing, mindfulness and yoga
- Engaging or enrolling in hobbies and activities
- Seeking professional help if needed.

3

Relationships and family

Feeling isolated after treatment

Many families feel a bit lost, even 'abandoned' after treatment by a health care team that seems to be more concerned with 'sick' families. It is important to remember that the hospital staff are still here to support you. It may be helpful to identify a key person, such as a nurse coordinator or social worker that you can call for extra advice or support at this time. It may also help to ensure your GP is kept informed.

Rebuilding relationships

You may feel that some of your 'pre-cancer' friends and family no longer understand your experiences or needs. Some parents find that maintaining relationships with other parents of children who have had cancer is a helpful way to process thoughts and feelings by sharing the experiences. Support groups are also very good in this regard. However, it is also just as important for you to connect with parents of children who have not had cancer in order to return to a normal life in the community. Giving this booklet to others to read may help friends and family begin to understand your needs and concerns.

Re-establishing the family to a 'new normal'

Take some time to regroup as a family – be aware and acknowledge the impact this journey may have had on your partner and other children. Remember everyone deals with emotions differently. Sometimes tensions can arise between family members who choose to deal with what has happened in different ways. Life of course will never return to exactly how it was before your child was ill. However, most parents feel that in time, the family reaches a 'new normal'.

Families also talk about the positives that come out of their cancer journey including closer relationships within the family and a renewed appreciation for life.

Siblings

Brothers and sisters may still have concerns about their sibling's health after treatment. They may also feel that parents are still focusing more on the child who has been ill. Some siblings may even have feelings of jealousy or resentment. Your other children often need the acknowledgement that they are loved equally. They need to be aware that there are no longer any signs of the cancer in their sibling.

Life doesn't go back to what it was before ... it just doesn't click into normal again, you're just going to have to take small steps

— Adolescent survivor

How do I communicate with my child about their cancer?

Your child may want to learn more about their cancer as they get older. Many will have been too young to remember or interpret the experience. You may feel tempted to protect your child from this, but children often have far more knowledge than their parents realise.

I'd been there and I knew what she'd had or what she'd seen and then I'd go 'but don't you remember?' and she'd go 'No, I don't remember that bit'. And I'd go, am I right or am I wrong to remind her, you know, if she has forgotten?

— Mother of childhood survivor

Talking to your child about their cancer allows them to share their thoughts and feelings as well. It may be a good idea when meeting with your oncologist at follow up to increasingly include your child into the conversation as they grow older. This will help correct any misunderstandings and give your child reassurance. It can also encourage them to ask questions and over time, take increasing responsibility for their health.

4

School

Returning to full-time school

For many children, getting back into the school environment full-time and its routines can be a difficult process. Factors such as changes in appearance, missed assignments, time spent away from school and changed perceptions of their old friends can create anxiety or fear. It may also be hard for you to let go and allow your child to become more independent again.

Returning to school, transitioning to secondary school, or coping with interrupted schooling can be challenging for any child and their family. There needs to be a consistent and on-going approach to supporting the educational needs of your child when they return to school after a long absence. It may be helpful to organise a meeting with the school principal to outline the expectations and responsibilities of everyone involved.

Some key areas that you and the school may need to discuss and plan are:

- Sharing information
- Completing a Student Health Support Plan
- Maintaining communication
- Making changes
- Seeking further support

If your hospital has a dedicated education advisor, they can play a role in supporting the transition back to school. You should contact your social worker or education advisor if you or your child need help with school issues.

Has the cancer treatment affected my child's ability to learn?

Many childhood cancer survivors will have no difficulties with their learning and thinking skills following treatment. However, some types of cancer, treatments and medical complications can impact on a child's cognitive (learning and thinking) development. Children who have had treatment for brain tumours as well as children with a history of leukaemia may be at higher risk of learning difficulties.

It is important to describe and monitor their progress. This may include a focus on skills such as attention, memory and learning. If you are concerned about your child's thinking and learning difficulties at any stage please discuss this with your oncologist.

The PICS have developed a series of booklets as a general reference guide for teachers, parents and carers to identify and address the thinking, learning and behavioural/emotional difficulties children and adolescents may experience following treatment for cancer. It is important to remember, not all children and adolescents will experience difficulties. The booklets are available from www.vics.org.au/pics.

5

Looking to the future

Healthy living following treatment

As your child starts to feel better, their interest in food and mealtimes should start to return to normal. During treatment they may have been encouraged to eat a high energy diet due to weight loss. Once they have regained their weight, it is time to return to their normal diet.

Your dietitian can help you normalise any changes to your child's diet and eating behaviours. Your child should be encouraged to maintain a healthy activity level. Thirty minutes of exercise a day, with parents leading by example, gets the whole family involved. Exercise is important for long term health and well-being while also reducing stress. Exercise and a healthy balanced diet are also important if your child has gained too much weight during treatment.

What about fertility?

Your child's fertility is dependent on the type of treatment they received. This may have been discussed at diagnosis. It is often hard to remember everything that was said in the beginning so it is best to ask your oncologist about fertility again at the next follow-up visit.

The Long Term Follow-up Program (LTFP)

At the end of the surveillance phase (after two years, depending on the type of treatment) patients can be referred to the Long Term Follow-Up Program (LTFP). Some treatments that cure cancer may cause health concerns, which may not be apparent until years later (called late effects). The LTF Program provides resources and education, through appointments for childhood cancer survivors, and is able to provide a summary of treatment that your child received. These tools, along with a co-ordinated plan for transition of care, can be used to help facilitate ownership of your child's ongoing follow-up and engagement with an adult hospital or a community health care provider such as your GP, as appropriate. Remember, the reason follow up goes on for many years is to be able to identify and manage any potential late effects, not because of a risk of relapse.

Contacts

Useful numbers

Included in this section is a short list of useful contacts and websites. There are many community organisations and support groups who offer services and programs for families and children when treatment has been completed. Please speak to your social worker for further information.

The Royal Children's Hospital

Children's Cancer Centre (Kookaburra Ward) (03) 9345 5645

Social Work (03) 9345 6111

Children's Cancer Centre Psycho-Oncology Team (03) 9345 5679

Dietitian (03) 9345 5663

**Children's Cancer Centre Leading Teacher, Education Support Team,
RCH Education Institute,** (03) 9322 5100

Long Term Follow-Up (03) 9345 9152 ltf.program@rch.org.au

Monash Children's Hospital

Children's Cancer Centre (03) 8572 3456

Social Work (03) 8558 9000

Dietitian (03) 8572 3003

All enquiries (03) 8572 3000

Long Term Follow-Up (03) 9345 9152 ltf.program@rch.org.au

Peter MacCallum Cancer Centre

Long Term Follow-Up Nurse Coordinator (03) 9656 1060

longtermfollowup@petermac.org www.petermac.org

Other useful contacts

Your local family doctor (GP) _____

Useful websites

Australian Cancer Survivorship Centre (Peter MacCallum)

www.petermac.org/services/support-services/australian-cancer-survivorship-centre

Australian Psychological Society (click on 'Find a Psychologist')

www.psychology.org.au

Cancer Council Victoria www.cancervic.org.au

Children's Cancer and Leukaemia Group (United Kingdom)

www.childcancer.org.uk

Cure Search for Children's Cancer (The Children's Oncology Group, North America) www.curesearch.org

Hope portal: a website of recommended childhood cancer internet resources developed by the Children's Hospital Los Angeles

www.searchhope.org

Lifeline www.lifeline.org.au

LIVESTRONG Foundation (North America) www.livestrong.org

Monash Children's Hospital www.monashchildrenshospital.org

Paediatric Integrated Cancer Service (PICS) www.vics.org.au/pics

The Royal Children's Hospital www.rch.org.au

The Children's Cancer Centres' Parents' Advisory Group

www.rch.org.au/ccc/parents_advisory_group/Parents_advisory_group/

Travel insurance information

www.chronicillness.org.au/workwelfarewills/

Youth Beyond Blue (young people and mental illness)

www.youthbeyondblue.com

Visit www.vics.org.au/pics for a complete list of links for further assistance

Books

There are a number of publications available for childhood cancer survivors. Please ask your nurse coordinator about access to these books or further information.

Childhood Cancer Survivors: A Practical Guide to Your Future

Patient-Centred Guides. 2nd Ed.

Nancy Keene, 2006

Let's Talk about It: Survivor Stories

Darren Neuberger, 2010

Looking Forward: Childhood Survivor Stories

CLIC Sargent Publications, 2007

The Other Side of the Mountain: A parent's guide to surviving childhood cancer

Visit www.thenccs.org under the 'education & resources' tab

Other Resources

Written resources for families

Visit www.vics.org.au/pics

Disclaimer

The information in this book is current as at July 2020. The information provides a brief overview and relevant contacts for families of children and adolescents cared for within Victoria, Australia. This information is not intended as a substitute for consultation with your healthcare team. For more advice regarding your child's care, please see your doctor.

For more information, visit www.vics.org.au/pics



Peter Mac
Peter MacCallum Cancer Centre
Victoria Australia



**The Royal Children's
Hospital Melbourne**