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## Introduction

A cancer diagnosis is difficult news for anyone to hear.

Being a mother of young children can add an extra layer of fear, guilt and trepidation to an already stressful situation. The Mummy's Wish Program is here to support these mums.

We created this guide to help mums feel supported, to encourage them to soften their expectations, and to empower them with information to help navigate family life during this challenging time.

It shares the advice of other mums who have been there, as well as the knowledge and experience of the Mummy's Wish team, gained over many years of supporting mums with cancer across Australia.

We hope this resource helps you feel less alone. We will do whatever it takes to be there for whatever you need.

# About Mummy's Wish

Mummy's Wish is a program of Rare Cancers Australia (RCA) that provides tailored and practical support for mums diagnosed with cancer who have young children.

We help to manage the distressing burden of cancer on mums and their families by offering information and resources including care packs, recordable comfort bears, educational books, informal counselling sessions, and financial support where needed. Further to this, every mum who comes into our care has complete access to Rare Cancers Australia's dedicated personalised support network, helping them to connect with others and navigate the health care system.

This support gives the gift of time to mums with cancer so they can focus on what's most important – being a mum.

## Where we are today

Mummy's Wish was founded in 2007 and since then, it has continued to develop and expand to meet needs of mums across Australia.

In early 2024, Mummy's Wish became a program of Rare Cancers Australia, continuing to support mums who are diagnosed with cancer and have young children. Our practical support eases some of the burden on mums, so they can be there for their family.

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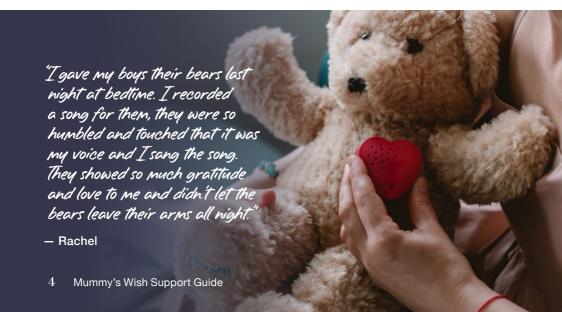
# How we can help

We believe that every mum diagnosed with cancer should feel supported so they can be there for their family. That's why we offer tailored and practical support for mums with young children, anywhere in Australia, during any stage of their cancer experience.

## Practical support

We do whatever it takes to be there for mums, offering support that is as unique and individual as you. Your own dedicated Mummy's Wish Support Coordinator can walk you through every step of your cancer experience, providing you with:

- Informal counselling sessions and supportive check ins, with someone who understands the challenges of trying to juggle a young family and cancer.
- A care pack that includes information and resources on how to manage cancer, books to help children understand cancer and treatment, and a voice-recordable comfort bear for each child.
- Direct assistance to keep your family functioning during cancer treatment.
- Referrals to other support agencies that could help meet your family's needs.
- Memory making tips and resources if you have been given a terminal prognosis.



Finding Mummy's
Wish was such a relief.
Just knowing there was
a free and easy-to-access
program available that
truly understood the reality
of balancing motherhood
and cancer treatment made
such a difference."



- Olga

As a program of <u>Rare Cancers Australia</u> (RCA), Mummy's Wish can also connect you with an RCA Specialist Cancer Navigator for further personalised support. This could include:



### **Clinical support**

Help understanding your diagnosis, navigating the healthcare system and treatment options, advocating for what you need, and accessing clinical trials.



### **Emotional support**

Supporting you through difficult decisions and complex relationship challenges.



### Peer support

Connecting you with others who understand, such as through our safe and welcoming support groups.



### Carers support

Guidance to carers on how to best take care of others, as well as themselves.

# Being a mum with cancer

## Feeling it all

If you are finding it challenging to cope emotionally right now, please know that you are not alone.

For many mums, a cancer diagnosis compounds the usual challenges of parenting. It can mean that you're torn between attending to your own needs, and the needs of your family. It can be difficult to help your children deal with the news of your diagnosis, especially if you're struggling yourself. This can lead to feelings of guilt, inadequacy, self-doubt or anger.

There is no right or wrong way to feel. Experiencing fear and anxiety is normal after a cancer diagnosis. You may feel sad, shocked, confused, or maybe even a bit numb.

Reaching out and talking through these feelings can help – there are people and organisations who understand what you are going through and are ready to support you.

You can find a list of these in the Helpful Resources section at the end of this guide.



# Having a tough time and need to talk right now?

Call a member of the Mummy's Wish team on 1800 257 600, or alternatively Lifeline is there to listen any time, day or night. You can call them on 13 11 14 for a confidential chat.



Please know that no matter how you feel, you are not alone. We have helped thousands of mothers across Australia facing a similar situation.

#### Here are some things they want you to know:

Your kids will be fine if they end up with take away or a bowl of cereal for dinner!"

Sometimes your house will be messy. It's okay! Take a deep breath and let it go."

Some days you may feel almost 'normal', we promise! But don't overdo it on those days. Your body is going through a lot."

Sometimes you won't be able to attend your children's events because of appointments, ill-health, or exhaustion – and that's ok! You are one person, and you can't do it all."

Your family will occasionally forget how sick you are and will sometimes ask for love in unloving ways."

It's okay to feel angry or sad that this is happening to you, and that other people seem to be happily getting on with their lives when it feels like yours is falling apart or will never be the same. In fact, it is normal."

I would encourage all mums who are struggling with a cancer diagnosis to ask for help. Just to have that initial chat and know you're not alone, that you're understood. It feels like a massive weight being lifted off your shoulders.'

### Taking care of yourself

Sometimes it can be hard to focus on yourself, especially when you're used to focusing on everyone around you.

Here are some tips from our Mummy's Wish Support Coordinators on managing your own wellbeing during this challenging time.

- Remember you are doing the best you can. Be kind to yourself and recognise that it is okay to have negative emotions.
- Try to recognise and label emotions. For example, "I am feeling really cranky with my partner, but actually what I am feeling is worry about tomorrow's appointment."
- Try not to make decisions or do research in a distressed state of mind.
- Consider talking to your doctor about meditation. It can help lower stress levels for some people.
- Try to get plenty of rest.
  Everything is more challenging when you are tired.
- Consider creating a gratitude journal. It's one way to focus on the small, everyday things that are positive in your life.
- Ask for help! Asking for help can be hard, but now is the time to accept it from those who care.

- Know who to contact when you're feeling wobbly, like a trusted support person, an oncology social worker, cancer navigator, counsellor, psychologist or crisis service.
- Write down your worries and questions. This can be really helpful to prevent you bottling them up.
- Consider techniques like grounding and mindfulness. These can be useful when you are anxious.
- If you can, try to incorporate movement into your day. This can help with balancing your mood and working through your emotions.
- Plan to have time for yourself doing something you love, which brings you joy.
- Connect with others that are going through a similar experience. This can help you feel understood and less alone. The organisation/s for your specific cancer may offer this.

### Connecting with mums who understand

Treatment schedules and geographical distance can make it tricky to connect with other mums with cancer. That's why we offer a private Mummy's Wish Facebook Group, as well as an online Support Group over Microsoft Teams, facilitated by one of our Support Coordinators. These are safe and welcoming spaces to have real conversations with other mums who understand the challenges and emotions that go with a cancer diagnosis.

<u>Contact our team</u> to learn more. Find our contact details on page 28.





# Leaning on your people

## Managing the day-to-day

When you're diagnosed with cancer, it can be normal to feel like your diagnosis is taking over your world. Between a busy treatment schedule, well-meaning family and friends, and managing your own emotions and symptoms, it can be a lot to manage. But you are not alone.

As a mum, you may be used to putting the needs of others before yourself, and it can be difficult to ask for – and accept – help. But building a support team that can help you manage day-to-day life can really take some pressure off.

For example, people wanting to know how you are and when you'll be 'better' may start to feel intrusive or draining. Consider nominating someone you trust to keep everyone in the loop and deal with these enquiries.

It's likely that your family and friends want to help in any way they can, but they may not know the best way to do so. Be specific about how people can support you, choosing activities that match their abilities and availability.



### Keeping things 'normal' at home

Life may change during your treatment, but where possible, try to keep familiar routines in place to help provide emotional safety for your kids. Keeping their days as 'normal' as possible won't work all the time, and hiccups are unavoidable, but people want to help and it is okay to ask.

Maintaining usual limits and boundaries around behaviour is also important; it may seem hard when you all feel pretty vulnerable and want to let things slide, however this consistency will help kids feel safe.



Some ways your work, school and social community may be able to help include:

- organising nutritious meals, school lunches or healthy snacks
- helping you get to and from treatment
- taking care of the school and sport pickup and drop off
- grocery shopping
- helping with the laundry, ironing or house cleaning
- arranging play dates for the kids
- taking photos and cheering on your kids at events if you're unable to be there.

Don't underestimate the value of friends who can just be there for you – listening without offering advice, getting you out and about, and having fun.

You can find more information on how people can support you in the <u>Helpful Resources</u> section [page 20] at the end of this guide.



### Communication and roles

If you have a spouse, partner or support person, they may feel just as anxious about your cancer diagnosis as you do.

It is okay to feel this way and it can be caused for a range of reasons, including:

- not knowing how to best support each other and how to communicate
- dealing with new feelings that come up
- making decisions
- juggling lots of roles (such as childcare, housekeeping, work, and care giving)
- changes to social life
- · changes to daily routine
- · not feeling connected sexually.

It can help to know that people express their emotions in different ways. Some like to talk about things or focus on other people, while others like to focus inward by doing things, such as washing the dishes or fixing things around the house.

These differences can cause tension because each person may expect the other to act the way they would in their place. To reduce stress, it may help to remind yourself that everyone reacts differently; some people find it easier to talk about serious issues than others.

#### Here are some tips that may help communication.



### Get on the same page

You need to be a team now more than ever. If you can, attend appointments together to learn about treatment options and side effects, and any decisions that need to be made. This will help you have a shared view of what the upcoming weeks and months may look like for your family.



### Accept support

You may have managed the household or taken care of the family's emotional needs most of the time. It may be hard at first, but now is the time to let your loved one support you in new ways. Letting them know you understand it's a tough time for them too will help them feel appreciated.



### Share your feelings

Some things that cause stress can't be solved right now, but it can still be helpful to get them out into the open. Taking turns sharing your hopes and fears can help you both feel heard, understood, and in this together.



### Make time together

Many couples find that it helps to plan special time together. These dates don't have to be fancy or expensive; it could be watching a movie or enjoying a meal together. This can be a nice respite from talking and thinking about cancer.

 You can find more information on managing relationships and cancer in the Helpful Resources section [page 20] at the end of this guide.

# Supporting your children

## Breaking the news

No one wants to upset a child or tell them worrying news. But no matter how young they are, children may sense that something is wrong.

They might notice changes in the normal routine, more people coming over, or switches in things like your energy levels.

The truth is best when it comes to children, in simple language that is appropriate for their age and personality. While there is no 'perfect' way to tell them about your cancer diagnosis, it can help to take some time to prepare. Think about the messages you want to relay and trust your instincts – you understand their needs and feelings best.



## Here are some tips on how to talk to your children about cancer.

- Provide a simple, clear explanation of your diagnosis in language they will understand.
- Let them know what to expect with regards to your treatment plan. Reassure them that someone will be there to look after them if you're in hospital or feeling unwell.
- Ask what they already know or believe. This may give you clues as to any concerns they have or misunderstandings you can clear up.
- Give simple, honest answers and clarify any confusion in plain language.
- Ask if they have any questions and encourage them to ask further questions any time. Often, kids feel more comfortable having these conversations in the car, taking the dog for a walk, or over dinner.
- Reassure them that cancer is no one's fault. Children might think something they did caused the cancer, or that they could catch it.
- Encourage talking about feelings and tell them it is okay to have a lot of emotions.

Mummy's Wish can help you to find age-appropriate books tailored to you circumstances that can help you talk to your children about your cancer.

- Express hope about your prognosis but try to balance this with the reality that cancer is a serious illness and that treatment can be difficult. It is not helpful to make promises you can't keep.
- Watch them carefully to sense how much they are able to digest you may notice little signals that tell you they have had enough for now.
- Make sure the key people in the child's life are on the same page.
- Provide positive things that will help them feel secure. For example, that the family can spend extra time together on the weekend.
- Try not to speak ill of your treating team it's important for children to know that the treating team is doing what's best, so they don't feel like it's an 'us versus them' situation.
- Provide extra expressions of love – both physical and verbal.
- You can find more information on talking to kids about cancer in the Helpful Resources section [page 20] at the end of this guide.

### Letting your child's school/childcare provider know

This template is helpful for breaking the news to others, so teachers can expect potential changes to your child's routine and provide some additional emotional support.

#### **DOWNLOAD TEMPLATE**

Dear <insert name here>.

I am writing to let you know that I have been diagnosed with <insert diagnosis here>.

<insert child's name> knows that I <am sick/have cancer> and we have told <him/her> that managing this will take some time and will involve <insert any relevant treatment details>. At home we refer to my illness as <insert whatever words you use at home when speaking of your illness> and the treatment as <insert words used by the child when talking about the treatment>.

We are keeping a close eye on <insert child's name> but would appreciate if you could also do so and get in touch if you have any concerns about a change in <child's name>'s behaviour. <insert partner's name if applicable> and I would also appreciate you letting us know if there is any curriculum content or school activities coming up that may be distressing to <child's name> so we can work together, in advance, on a course of action to manage this.

My intention is to keep you up to date with my treatment progress on a regular basis to ensure that we can work together to make this as easy as possible for <child's name>, the teaching team, school community and our family. We <would prefer at this stage to keep the news of my diagnosis fairly guiet / we are comfortable if <child's name>'s classmates and families know of my diagnosis>.

I have mentioned to <child's name> that I am sending this through to you and they have indicated that they are <happy for you to check in on them occasionally to see how <he/she's> coping / they would prefer school to be a place where <he/she> does not need to worry about my health and just focus on school.>

My treatment is going to be busy and challenging, so I have asked <insert name of friend or family member> to be the point of contact for those wanting to reach me with messages, offerings of help or questions. <He/she> can be contacted on <insert contact details>.

Thank you for all that you do for <child's name> and thank you for your understanding and cooperation during this time.

Yours sincerely,

<insert name>



### Keeping the joy alive

Mums don't generally get to take sick days, but when you're going through treatment for cancer, there will be days when you just can't get up and go.

Here are some fun ideas for younger children that require minimal participation on your part – so you can rest and recover while they are happily occupied.

## 1 Indoor picnic

Pop a doona or blanket down on the floor, cover it with pillows and let them have a picnic with snacks, or make some popcorn and put on a movie or their favourite TV show.

## 2 Story time

The perfect activity to snuggle up together on the couch or in bed. Ask them to read it back to you or re-tell the story in their own way.

## 3 Indoor camping

Set up a pop-up tent indoors (or throw a blanket over the dining table), fill it with blankets, pillows, a torch and their favourite books and pretend you're camping. They can pretend to sleep under the stars, sing around a campfire or just hide out while you doze nearby.

## 4 Rainy day box

Set aside some special colouring or activity books, toys or activities that they don't usually have access to. Pull these out on the days you're struggling so they have something new to do.

## 5 Indoor bowling

Buy a cheap indoor bowling set for kids, or save up some empty plastic bottles, line them up at the end of your hallway and set the task of knocking them down with a soft ball.

## 6 Scavenger hunt

If your kids can roam around the house unsupervised without getting into too much trouble, send them on a scavenger hunt. Depending on their age, you could write them a list of things to find, or if they're younger, send them off to find items of a particular colour.



### 7 Balloon art



Blow up a few balloons and have your child draw on faces using permanent markers. You can even ask them to draw the members of your family or your pets!

## 8 Board games

Card games like Uno or Go Fish and any of the quieter board games (snakes and ladders) are great because they don't require you to move around too much.

## 9 Fashion parade



Kids love any opportunity to dress up, so let them loose to dress themselves from either their wardrobe or yours! You can even set them a task to wear X amount of pieces at once before parading them for you.

## 10 Podcasts

power nap is enough to get you through the rest of the day.

Get the kids listening to podcasts. There are so many topics to choose from. No matter what your child is interested in, there is a podcast for them.

## 11 Audio books

Sign up to Audible and listen to audiobooks together. Or for a free option, download audiobooks from your local library.

## 12 Kids yoga session

Search for Cosmic Kids Yoga on YouTube. This fun series makes mindfulness relevant to kids, helping them develop awareness of their emotions and techniques for self-regulation.

# Helpful resources

### Online

### Diagnosis and Treatment

Title	Organisation	How it can help	Link
Rare Cancers	Rare Cancers Australia	Support, information and guidance for people with a rare cancer, or common cancers that require additional support	www.rarecancers.org.au
Knowledge Base	Rare Cancers Australia	List of cancers and relevant information on them	www.rarecancers.org.au/ knowledgebase/
Support Guide – Diagnosis	Rare Cancers Australia	What to expect after a diagnosis, questions to ask, where to find more information, advice on managing difficult emotions, understanding your rights	www.rarecancers.org.au/ information-and-support/ rare-cancer-support-guide/ diagnosis-booklet/
Support Guide – Treatment	Rare Cancers Australia	Planning for treatment, managing work and finances, what to do when treatments aren't available, how to navigate the health system, the science of cancer	www.rarecancers.org.au/ information-and-support/ rare-cancer-support-guide/ treatment-booklet/
Glossary of Terms	Rare Cancers Australia	A glossary of terms you may hear during your diagnosis and treatment	www.rarecancers.org.au/ resources/glossary/
Understanding your Diagnosis	American Cancer Society	An online guide with information for people diagnosed with cancer, including treatment options and services	www.cancer.org/treatment/ understanding-your- diagnosis.html

Title	Organisation	How it can help	Link
Questions to Ask	American Cancer Society	List of suggested questions to ask when first diagnosed with cancer	www.cancer.org/content/ dam/cancer-org/cancer- control/en/worksheets/ questions-to-ask-about-my- cancer.pdf
Prognosis	National Cancer Institute	A guide to understanding your cancer prognosis	www.cancer.gov/about- cancer/diagnosis-staging/ prognosis

## **Managing Emotions**

Title	Organisation	How it can help	Link
Support Service	Beyond Blue	One-on-one call with a trained mental health professional who can assist you in finding care	www.beyondblue.org.au
What is Anxiety	American Cancer Society	Recommendations on coping with stress, anxiety, and uncertainty after a cancer diagnosis	www.cancer.net/coping- with-cancer/managing- emotions/anxiety
After a Diagnosis	Cancer Council	Guide to helping you and your loved ones to cope with a cancer diagnosis	www.cancer.org.au/ cancer-information/ after-a-diagnosis
Managing Emotional Changes due to Cancer	Cancer Australia	Information about emotions experienced during the course of a cancer diagnosis	www.canceraustralia.gov. au/impacted-by-cancer/ emotions
Feelings and Cancer	National Cancer Institute	Information about feelings that may be experienced during a cancer diagnosis	www.cancer.gov/about- cancer/coping/feelings

Title	Organisation	How it can help	Link
Emotions and Cancer	Cancer Council	A guide to help people understand the emotional impact of cancer, including an Emotional Impact Toolbox	www.cancercouncil.com. au/cancer-information/ coping-with-a-diagnosis/ emotions-and- cancer/#challenging-times
Support and Services	Cancer Council	A comprehensive range of support services for all people, affected by all cancers, across Australia	www.cancer.org.au/ support-and-services
Camp Quality	Camp Quality	Support for young children aged 13 years and under in dealing with the effect of cancer in their lives	www.campquality.org.au
CanTeen	CanTeen	Support for young people aged 12 to 24 years in dealing with the effect of cancer in their lives	www.canteen.org.au
What about me?	Cancer Council QLD	The book provides basic information and explores the possible feelings, fears and concerns your children may have	https://resources. cancerqld.org.au/products/ what-about-me-for- children-when-a-parent- has-cancer
Dealing with your parent's cancer	CanTeen	Addresses the questions, feelings and new thoughts running through your head	www.canteen.org.au/how- we-help/books-resources
Picture books about feelings and worries	Little Parachutes	Picture books that help kids cope with worries, health issues and new experiences	www.littleparachutes.com/

## Relationships and Support

Title	Organisation	How it can help	Link
Support Guide  - Relationships and Support	Rare Cancers Australia	Breaking the news, how to care for yourself and others, and maintaining your important relationships	www.rarecancers.org.au/ information-and-support/ rare-cancer-support-guide/ relationships-and-support- booklet/
Cancer Support and Work	My Muse	Advice to cancer patients and carers to successfully return to/or remain in the workplace	www.mymuse.com.au
Helping Children when a Family Member has Cancer	American Cancer Society	How to talk to children about a family member living with cancer	www.cancer.org/cancer/ caregivers/helping- children-when-a-family- member-has-cancer/ dealing-with-treatment.html
Telling Others About Your Cancer	American Cancer Society	Telling others about your cancer and how to manage reactions/expectations	www.cancer.org/cancer/ diagnosis-staging/ telling-others-about-your- cancer.html
Sexual Intimacy and Cancer	Cancer Council	How cancer and treatment may affect your sex life	www.cancercouncil.com. au/cancer-information/ managing-cancer-side- effects/sexuality-intimacy/
A Way to Help Manage Your Carers	Lotsa Helping Hands	An online resource to provide ways your carers and support network can help you	https://lotsahelpinghands.com
Caring for Someone with Cancer	Cancer Council NSW	Explains the carer's role and offers practical tips for balancing the demands of caring with your own needs	www.cancercouncil.com. au/cancer-information/ carers/caring-for- someone-with-cancer
Talking to Kids About Cancer	Cancer Council	A guide for people with cancer, their families and friends	www.cancer.org.au/ cancer-information/ types-of-cancer/childhood- cancers/talking-to-kids- about-cancer

Title	Organisation	How it can help	Link
What is Happening to my Mummy	Cancer Council QLD	An interactive story book to help children with a parent who has cancer	https://resources. cancerqld.org.au/products/ what-is-happening-to-my- mummy
Telling Your Children	Breast Cancer Network Australia	Things that can help, things that probably won't help	www.bcna.org.au/ resource-hub/articles/ telling-your-children/
Helping a friend or colleague with breast cancer	Breast Cancer Network Australia	Emotional help, practical help, the workplace, things that won't help	www.bcna.org.au/ resource-hub/articles/ helping-a-friend-or- colleague-with-breast- cancer/
Family and Friends Brochure	Ovarian Cancer Australia	A brochure for family and friends of someone diagnosed with ovarian cancer	https://shop.ovariancancer. net.au/products/family- and-friends-brochure



### Children's Books



### When Someone Has A Very Serious Illness

by Marge Heegaard

A practical workbook to help children learn the basic concepts of illness and age-appropriate ways of coping with it.



#### **Hey Warrior**

by Karen Young

Designed to empower children to manage feelings of anxiety.



#### Nowhere Hair

by Sue Glader

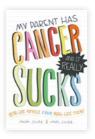
Offers a comfortable way to talk about hair loss, cancer and start a conversation with young children.



### The Invisible String

by Patrice Karst

A picture book offering a child-centred approach to overcoming separation fears.



### My Parent Has Cancer and It Really Sucks

by Maya Silver & Marc Silver

A tool kit for teens coping with a parent's cancer diagnosis - including a section for parents.

# How you can help

By supporting Mummy's Wish, you are helping more mums with cancer access tailored and practical support for themselves and their young families.

Here are some of the ways you can help us continue this important work.



To support Mummy's Wish, scan this QR code or visit https://mummyswish. org.au/support-us/



#### Donate a Comfort Bear

If you found the comfort bear helpful, encourage people you know to donate just \$75, so that more mums can receive this special gift.



#### **Fundraise**

Organise an event or activity (big or small!) that raises awareness about the impact of cancer on mums and supports the work we do. We can help with ideas if you're not sure where to start.



### Share your story

Reading the stories of other mums impacted by cancer can provide insight and comfort – and remind people that they are not alone. It can also help to raise awareness of cancer in women, and the need for tailored and practical support for mums.

If you would like to share your story, we would love to hear from you. Please email contact@mummyswish.org.au



Read some of our mum's stories at https://mummyswish. org.au/category/ mums-stories/ or scan this QR code.





#### Volunteer

RCA has been running a Mummy's Wish Volunteer Program since April 2024. The main task of our volunteers has been stuffing our Mummy's Wish bears, getting them ready to be sent to our mums and families. Each bear has been stuffed with love and care and has been given a little cuddle of support before being sent. This important work enables Mummy's Wish to continue sending care packs out to our mums in a timely manner, allowing them to provide their children with beautiful comfort bears and recordable messages while they are receiving treatment.

The continuation of the Mummy's Wish care packs would be hard to achieve without the wonderful help of our volunteers! If you'd like to help, please email <a href="mailto:contact@mummyswish.org.au">contact@mummyswish.org.au</a>



### Contact us

Send an email contact@mummyswish.org.au

Give us a call 1800 257 600

Send a letter
PO Box 440, Bowral,
New South Wales, 2576
(care of Rare Cancers Australia, Secretariat)

### www.mummyswish.org.au

- @mummyswish
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- in /mummy's-wish-inc