

Emotional wellbeing support guide

Recognising what feels heavy, and what support might help when living with inherited cancer risk

This guide can help you notice what feels most relevant right now, think about how much support might help, and choose one next step.

Start with the five areas below. You may relate to more than one section. That is completely okay. Begin wherever feels most important today.

Waiting and uncertainty around appointments

You may be thinking about appointments, screening, symptoms, body changes, surveillance or waiting for results.

Navigating medical decisions

You may be weighing up options around screening, surgery, medication, fertility, timing or what needs to happen next.

Family conversations and responsibility

You may be thinking about family conversations, what to share, or what inherited cancer risk could mean for people close to you.

Body changes, fertility and identity

You may be adjusting to changes related to your body, hormones, fertility, relationships, sexuality, confidence or sense of self.

The ongoing emotional impact

You may be thinking about the longer-term emotional impact of inherited cancer risk.

Notice how much support might help

Gentle Support

When things feel mostly manageable, but something is still on your mind. You may want clearer information, self-led tools, lived experience stories, reassurance, or support preparing for an appointment.

Extra Support

When worries keep coming back or feel harder to manage on your own. You might benefit from speaking with someone, sorting through information, connecting with peers, or working through the next step.

Stronger Support

When things are starting to affect daily life or feel difficult to manage alone. You may benefit from ongoing professional support, practical help, regular check-ins, or support from more than one service or person.

Need support right away?

You can use these support lines if you need someone to speak with now, or if things feel hard to manage on your own.

- Beyond Blue 1300 22 4636: mental health support by phone or online chat
- Lifeline 13 11 14: 24/7 crisis support
- 13YARN 13 92 76: 24/7 support from Aboriginal and Torres Strait Islander Crisis Supporters



Scan to find ICA resources, lived experience stories and support services mentioned in this guide.

inheritedcancers.org.au/experience

 **inherited**
CANCERS AUSTRALIA



Australian Government
Cancer Australia

The project is funded by the Australian Government through Cancer Australia.



Waiting and uncertainty around appointments

Appointments, surveillance and waiting for results can take up mental space, even when care is routine or planned. This might include high-risk surveillance, regular check-ups, surgery-related appointments, symptoms, body changes or waiting for results.

What kind of support might fit?



GENTLE SUPPORT

Things feel mostly manageable.

Self-led support may be enough for now.

- You feel unsettled and want clearer information about what to expect.
- “What if” thoughts are showing up, but still feel manageable most of the time.
- You would like help preparing for an appointment, scan, test or result.



EXTRA SUPPORT

Worries keep coming back.

It may help to speak with someone.

- Waiting for an appointment or result is staying on your mind.
- You would like reassurance from a person, not just written information.
- You are unsure whether to call, wait, book in or ask for more information.



STRONGER SUPPORT

This is affecting daily life. Ongoing or professional support may help.

- Worry about appointments, symptoms or results is affecting sleep, concentration, work, parenting, relationships or daily routines.
- Brief reassurance helps in the moment, but the worry comes back quickly.
- You may need regular check-ins, practical help or support from more than one person or service.

Support options that may help

You can use any of these options at any level of support. Start with the one that feels most useful.



SELF-LED TOOLS AND RESOURCES

- **Scanxiety Support Toolkit:** for support around scans, tests, surveillance and waiting for results
- **Grounding & Calming Exercises:** for moments when worry feels hard to settle.
- **Health Conversation Guide or question lists:** to prepare what you want to ask.
- **Evidence-Based Resource Centre:** clear information about inherited cancer risk and support options.
- **Lived experience stories:** read how others have managed similar moments, at your own pace.



CONNECTION AND ICA SUPPORT

- **ICA National Online Support Group:** ask questions and hear how others navigate similar worries and what may help.
- **Inherited Cancer Support Service:** speak with ICA's genetic counsellor about what to ask, what to expect or what your next step could be.
- **Peer Support Program:** connect with a trained mentor for one-to-one support and lived insight.
- **Someone you trust:** ask for help with transport, childcare, follow-up calls or support before or after an appointment, so there is one less thing to manage.



HEALTHCARE AND PROFESSIONAL SUPPORT

- **Book a GP appointment,** even if a specialist appointment is already scheduled
- **Ask your GP about a mental health treatment plan,** including referral options for ongoing support
- **Tell your care team,** if surgery or cancer treatment is part of your care, that waiting, appointments or results are affecting daily life

Navigating medical decisions

Living with inherited cancer risk can involve decisions that feel complex and deeply personal. This might include decisions about surveillance, risk-reducing surgery, medication, fertility, family planning, timing, work, parenting, relationships or what feels right for your future.

What kind of support might fit?

GENTLE SUPPORT

Things feel mostly manageable.
Self-led support may be enough for now.

- You want clearer information about your options.
- You are weighing up timing, next steps or what questions to ask.
- You would like to feel more prepared before an appointment or decision.

EXTRA SUPPORT

Worries keep coming back.
It may help to speak with someone.

- You keep going over the same options and want to talk it through.
- You are unsure what information applies to you.
- You would like support understanding how this decision may affect your life, family or future.

STRONGER SUPPORT

This is affecting daily life. Ongoing or professional support may help.

- The decision is affecting sleep, work, study, parenting, relationships or sense of self.
- You feel stuck, overwhelmed or unsure how to move forward.
- You have had conversations or appointments, but still need more structured support.

Support options that may help

You can use any of these options at any level of support. Start with the one that feels most useful.

SELF-LED TOOLS AND RESOURCES

- **Evidence-Based Resource Centre:** reliable information about inherited cancer risk to support informed decisions.
- **Health Conversation Guide or question lists:** to prepare what you want to ask.
- **Lived experience stories:** read how others have approached similar decisions, at your own pace.
- **Decision notes:** write down what you know, what feels unclear, what matters most and what can wait.

CONNECTION AND ICA SUPPORT

- **ICA National Online Support Group:** ask questions and hear how others approached similar decisions.
- **Peer Support Program:** connect with a trained mentor for one-to-one support, personalised resource suggestions and lived insight around decision-making.
- **Inherited Cancer Support Service:** speak with ICA's genetic counsellor about information, options or questions for your care team
- **Someone you trust:** ask them to attend an appointment, take notes or talk through options afterwards, so you do not have to hold all the information alone.

HEALTHCARE AND PROFESSIONAL SUPPORT

- **Ask your genetic counsellor or care team** what can be broken down, paused or explained again.
- **Book a GP appointment** if the decision is affecting your emotional wellbeing or daily life.
- **Ask your GP about a mental health treatment plan,** including referral options for ongoing support.



Family conversations and responsibility

Inherited cancer risk can affect more than one person, which can make family conversations feel complex. You may be thinking about what to share, when to share it, who needs to know, how people might respond, or what this could mean for children, future children, relatives, or people close to you.

What kind of support might fit?



GENTLE SUPPORT

Things feel mostly manageable.

Self-led support may be enough for now.

- You want clearer information about what family members may need to know.
- You are thinking about how to explain inherited cancer risk in a simple way.
- You would like something written to help you start.



EXTRA SUPPORT

Worries keep coming back.

It may help to speak with someone.

- Family questions or conversations are staying on your mind.
- You feel unsure what is yours to share, what is yours to carry, or how much responsibility sits with you.
- You would like to talk through how to approach this with someone.



STRONGER SUPPORT

This is affecting daily life. Ongoing or professional support may help.

- Family conversations, different responses or responsibilities are affecting sleep, relationships, parenting, caring responsibilities or daily life.
- You feel responsible for how others respond or what they choose to do.
- One conversation helps briefly, but the worry, pressure or uncertainty quickly returns.

Support options that may help

You can use any of these options at any level of support. Start with the one that feels most useful.



SELF-LED TOOLS AND RESOURCES

- **Sharing genetic information with family:** support for planning what to say and how to start.
- **Family conversation templates:** written support to help you get started.
- **Lived experience stories:** read how others have navigated family and inherited risk, at your own pace.
- **One small starting point:** choose one person, one message or one piece of information to begin with.



CONNECTION AND ICA SUPPORT

- **ICA National Online Support Group:** ask questions and hear how others approached family conversations.
- **Inherited Cancer Support Service:** speak with ICA's genetic counsellor for personal guidance and practical resources.
- **Peer Support Program:** connect with a trained mentor for one-to-one support, and lived insight on how to approach these conversations.
- **Someone you trust:** ask them to help you practise what you want to say, sit with you before a conversation, or check in afterwards, so you do not have to navigate it alone.



HEALTHCARE AND PROFESSIONAL SUPPORT

- **Book a GP appointment** if the family side of inherited risk is affecting your emotional wellbeing.
- **Ask your GP about a mental health treatment plan,** including referral options for ongoing support.
- **Ask your GP or counsellor about family counselling,** relationship support or fertility counselling, if relevant.

Body changes, fertility and identity

Living with inherited cancer risk can affect how you feel about your body, relationships, fertility, sexuality, identity and future. You may be thinking ahead, making decisions, or adjusting after surgery, cancer treatment, recovery, medically induced menopause, or ongoing care.

What kind of support might fit?

GENTLE SUPPORT

Things feel mostly manageable.
Self-led support may be enough for now.

- You are adjusting to changes in your body, hormones, fertility, confidence or sense of self.
- You are looking for gentle information, lived experience stories or practical tips from people who understand.
- You are still managing day to day, but this is on your mind.

EXTRA SUPPORT

Worries keep coming back.
It may help to speak with someone.

- Changes to your body, fertility, relationships or identity are staying on your mind.
- You would like to talk with someone, ask questions or better understand what support is available.
- You may want help with practical next steps, such as managing symptoms, preparing for recovery, exploring fertility options or talking with a partner.

STRONGER SUPPORT

This is affecting daily life. Ongoing or professional support may help.

- These changes are affecting sleep, work, study, parenting, relationships, intimacy or daily life.
- You feel weighed down by what has changed, or by decisions that may affect your future.
- You may benefit from ongoing support from more than one person or service.

Support options that may help

You can use any of these options at any level of support. Start with the one that feels most useful.

SELF-LED TOOLS AND RESOURCES

- **Evidence-Based Resource Centre:** practical resources on body acceptance, relationships and intimacy, IVF and Preimplantation Genetic Testing, and medically induced menopause.
- **Lived experience stories:** read how others have navigated body, fertility or identity changes, at your own pace.

CONNECTION AND ICA SUPPORT

- **Peer Support Program:** connect with a trained mentor for one-to-one support and lived insight.
- **Inherited Cancer Support Service:** speak with ICA's genetic counsellor for personalised guidance.
- **ICA National Online Support Group:** ask questions and hear how others approached similar experiences.
- **Someone you trust:** ask them to help you write down questions, prepare for a sensitive appointment or come with you if you want support raising body, fertility, intimacy or relationship concerns.

HEALTHCARE AND PROFESSIONAL SUPPORT

- **Book a GP appointment** if this is affecting your emotional wellbeing or daily life
- **Ask your GP about a mental health treatment plan,** including referral options for ongoing support.
- **Ask your GP, or care team if surgery or cancer treatment is part of your care, about specialist support** such as fertility counselling, relationship counselling, sexual health support, menopause support, pain management, physiotherapy or rehabilitation.

The ongoing emotional impact

Living with inherited cancer risk can involve ongoing information, appointments, decisions, family considerations and future planning. Over time, keeping track of your health and care can become mentally tiring, especially when the experience is not always easy to explain to others.

What kind of support might fit?

GENTLE SUPPORT

Things feel mostly manageable.
Self-led support may be enough for now.

- Thoughts or feelings connected to inherited cancer risk are in the background.
- You feel mentally tired, but things are still mostly manageable day to day.
- You would like gentle information, lived experience stories or simple tools to feel less alone.

EXTRA SUPPORT

Worries keep coming back.
It may help to speak with someone.

- These thoughts or feelings keep coming back and are harder to shift.
- You are finding it harder to know what would actually help right now.
- You would like to talk with someone who understands inherited cancer risk, without needing to explain everything from the beginning.

STRONGER SUPPORT

This is affecting daily life. Ongoing or professional support may help.

- The ongoing mental impact is affecting sleep, work, study, parenting, relationships or your sense of self.
- You feel stuck, disconnected, or like you are managing too much without enough support.
- You may benefit from regular support, practical help or support from more than one person or service.

Support options that may help

You can use any of these options at any level of support. Start with the one that feels most useful.

SELF-LED TOOLS AND RESOURCES

- **Grounding & Calming Exercises:** support for moments when thoughts or feelings are hard to settle.
- **Health Conversation Guide:** prompts to check in with yourself and what support may help.
- **Creative Expressions:** writing, drawing or music to help name what is on your mind.
- **Lived experience stories:** read how others live with inherited cancer risk over time, at your own pace.
- **One small check-in:** write down what feels hardest to manage this week, and one support that could make it easier.

CONNECTION AND ICA SUPPORT

- **ICA National Online Support Group:** ask questions and hear how others manage the ongoing emotional side of inherited cancer risk.
- **Peer Support Program:** connect with a trained mentor for one-to-one support especially when worries feel private or hard to share publicly.
- **Inherited Cancer Support Service:** speak with ICA's genetic counsellor if you want help making sense of ongoing questions, future planning or what support might fit.
- **Someone you trust:** ask for regular check-ins or practical help with reminders, appointments, forms, childcare or planning, so you are not managing every step alone.

HEALTHCARE AND PROFESSIONAL SUPPORT

- **Book a GP appointment** if inherited cancer risk is affecting your emotional wellbeing or daily life.
- **Ask your GP about a mental health treatment plan,** including referral options for ongoing support.
- **Tell your genetic counsellor or care team** if ongoing worry is affecting appointments, surveillance or decisions.