

He waka  
eke noa

**brain  
tumour  
supportNZ**  
In it together



# He Kete Āwhina Training Handbook for Support Friends

TRAINING HANDBOOK

# Contents

<b>Welcome</b>	03
Becoming a Support Friend	04
Introduction - Being a Support Friend	05
<b>The Role of a Support Friend</b>	
Personal Attributes	07
Core Skills	08
<b>Support Friend Guidelines</b>	
Getting Started	10
Active Listening	12
Supporting Through Tough Times	14
Different Levels of Need	16
Dealing with Distressing Feelings	18
Suicidal Thoughts and Risk	22
Possible Pitfalls	24
Common Questions	25
<b>Useful Resources</b>	
Contact Numbers	26
Books and Resources	26
Acknowledgements	28

# Welcome to the Support Friends Programme

Thank you for joining our team.

**He waka eke noa, meaning “we are in it together”, highlights the purpose and values behind this programme.**

The diagnosis of a brain tumour is the start of a journey that nobody expects or wants to take. In New Zealand, around 10,000 people are living with a brain tumour and more are being diagnosed every day. Unfortunately our brain tumour community is growing.

There are over 130 different types of brain tumours, some more common than others. People of any age, gender, demographic or current health status can get brain tumours. The journey for everyone can be very different depending on their diagnosis and planned treatment. Despite this diversity, we do know there is a strong commonality in experiences, in particular that people often report feeling worried, stressed, grieving and lacking support.

The philosophy behind the Support Friends programme is to try to address this support gap. Brain Tumour Support NZ (BTSNZ) recognises the need for increased support for patients, carers, and family members. The Support Friends programme has been developed to provide training, support and resources to people within the brain tumour community who would like to offer this vital support to others.

**From The Brain Tumour Support NZ Team**



# Becoming a Support Friend

After indicating your interest in becoming a Support Friend we request some basic information from you. All information given to BTSNZ is kept confidential and is never shared outside BTSNZ. Information shared with Supportees (people requesting support) is limited to that which helps facilitate the match with a Support Friend. After completing your application you will be contacted by BTSNZ for a brief screening phone call. All Support Friends must be police vetted and undergo our online training session. Once accepted into the programme you will be provided with dates for training.

As part of the Support Friends Programme, BTSNZ will be seeking feedback from both Support Friends and Supportees. This will involve completing an online survey requesting information regarding your experience of the programme and to specify any support you may require.





# Introduction

**A brain tumour diagnosis is a life-altering event. Each person will have a unique journey and outcome. Each person will also have variable levels of support and understanding around them. Many find that family and friends can struggle to fully appreciate and comprehend the impact of a brain tumour diagnosis on both the patients and their loved ones.**

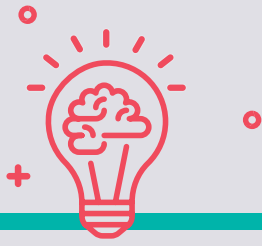
The Support Friend Programme aims to provide support to patients and carers by pairing them with a trained Support Friend who has had similar experiences. The power of being able to talk to someone who has “walked in your shoes” cannot be underestimated. Support Friends are trained to develop positive supportive connections with others which can range from the occasional phone call or text to lifelong friendships.

All Support Friends will participate in a training workshop which will have the following goals –

- Support Friends will understand their role and its purpose
- Support Friends will understand the limitations of their role
- Support Friends will have an opportunity to develop core skills to assist them in their role
- Support Friends will be provided with guidance for managing challenging situations
- Support Friends will learn about BTSNZ and its values and purpose
- Support Friends will understand what support and resources they can access if needed in their role

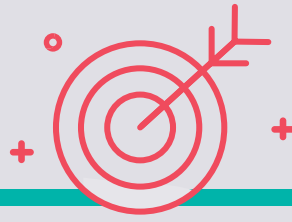
This handbook includes information and resources for you to use in your role as a Support Friend. We encourage you to use the handbook during your training workshop – write down ideas or questions you have during the training. The handbook is intended as an ongoing resource for you during your role.





## Our Vision

Everyone living with a brain tumour has the support, information and access to best treatments, so they feel less afraid, less alone and more empowered.



## Our Mission

We will inform, support and advocate for New Zealand brain tumour patients, their friends, family and whānau.



## Our Values

Our values create a moral compass for our trust and everyone who works with us. It guides our decision-making and how we are with others. These core values are our framework that we share and should be acted on by all.

### WE WILL BE...

- Inclusive
- Supportive
- Compassionate
- Honest
- Respectful

# The Role of a Support Friend

## Personal Attributes

The role of a Support Friend means being emotionally available to others. This requires having a stable life themselves as well as being available to offer support on a regular basis. Support Friends require a level of maturity, so must be 18 years of age or older.

### EXERCISE 1

In pairs, consider the following and share your experiences (5 min). Write notes if you like.

A. Think about a time when you felt unsupported by a friend/colleague/manager. How did you feel?

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B. Think about a time when you felt listened to and nurtured by a friend/colleague/manager. What did you notice about the other person that was different from the above scenario? How did you feel?

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Basic personal attributes needed in any supportive/counselling role include -

- Warm and caring
- Sensitive to the needs of others
- Non-judgemental

What other attributes would you add to this list?

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## Core Skills as a Support Friend

Alongside important personal attributes, there are also specific skills you can bring to the role of a Support Friend that will help ensure the connection between you and your Supportee is a positive and helpful one.

### EXERCISE 2

Discuss in pairs (5 min)

Think about what you want from a friend or colleague when you are upset and wanting support from them. Think of a time when this happened. What was particularly helpful about how the person supported you?

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In the Support Friends Programme we expect you to use the following skills.

### SUPPORT FRIENDS...

- Listen and create a safe space for sharing
- Accept and acknowledge difficult feelings
- Share own experiences where and when appropriate
- Be available to discuss ideas regarding coping with symptoms or treatment, handling practical concerns
- Help people problem solve around changes in roles, relationships, lifestyles, and finances
- Support those who are grieving
- Understand and maintain confidentiality and boundaries





# Support Friend Guidelines

## 1 Getting started with your Supportee

**Keep it simple – remember just the connection you are making and your ability to listen will make a big difference for your Supportee.**

### HELPFUL TIPS:

- Don't feel you have to be an expert – your Supportee is an expert in their situation – your role is to be a caring, listening ear
- Use a warm, friendly tone of voice to help them relax
- Use open-ended questions\* to get things started –
  - “Tell me what’s been happening with your brain tumour journey”
  - “Tell me about yourself”
- Be open to hearing about their brain tumour experience - it may be the first time they have opened up to someone about this
- If you have had similar experiences, you can share these but on the whole your goal is to follow their lead. Avoid allowing your sharing to take over – this is about them
- Remember your experiences could be similar but you should avoid making assumptions about how they feel or think about their experience – it could be very different for them. If in doubt, ask!
- They might have lots of questions. Where possible you can answer these from your own experience. Remind them you are not a medical professional or expert in brain tumours
- Allow silence – your Supportee may not have a lot to say or is struggling with feelings. Silence is an opportunity for you both to process thoughts and feelings and get comfortable in the space you share

*(\*closed questions require yes/no answers, open ended questions do not)*

### EXERCISE

Write down which of these you think you might find the most challenging. Share briefly in pairs.

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**General structure of contacts with your Supportee**

**Beginning**

- Warm and friendly
- Open ended questions

**Support**

- Listen more than talk
- Encourage sharing
- Feelings are ok
- Reflect and validate
- Problem solve as needed

**Closing**

- Transition, not sudden ending
- Convey hope
- Discuss follow up contact

## 2 Active Listening

**Listening is one of the most essential skills a Support Friend can have. Active listening is a technique which ensures you are being most effective in supporting another person.**



### HELPFUL TIPS:

- Give them your full attention:
  - Remove distractions so that you can be present
  - Avoid planning what you are going to say next
  - Notice the Supportee's word choices
  - Pay attention to non-verbal communication (e.g. tone of voice)
- Be non-judgmental:
  - If you disagree with something they say, that's OK. You don't have to convince them of your view. Instead acknowledge their view and share your related experiences
- Show you are listening:
  - Give signs that you're listening by saying "I see" or "Mhmm" now and again to help them feel heard
- Reflect their thoughts/feelings:
  - Summarise and reflect what they say periodically. Again this helps them feel heard. Ask questions for clarity (e.g., "What do you mean when you say you feel 'stuck'?")
- Acknowledge feelings
  - Hearing someone acknowledge how you feel is very powerful and validating. (e.g., "That sounds scary")
- Be authentic
  - Be genuine in your reflections and support. Being yourself even if you don't necessarily agree with everything they are saying is important. Remember honesty without judgment. Find a balance between their sharing and yours
- Avoid giving advice unless it is asked for



## VIDEO

Group discussion – what did you notice was particularly ineffective or effective for the person needing support in these videos?

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## TOP TIP!

It's OK to experience difficult feelings – they will pass

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## 3 Supporting through tough times

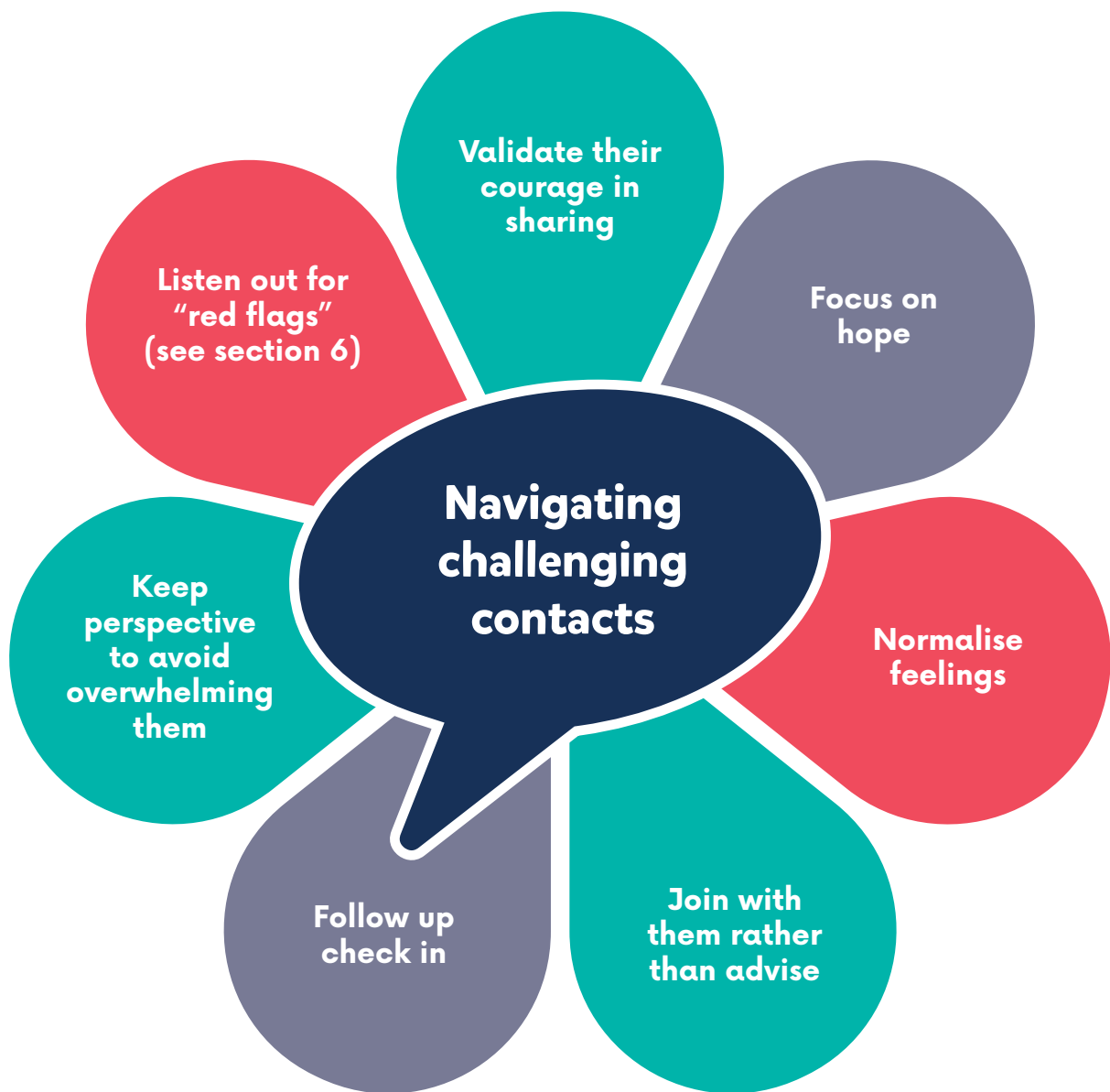
Living with a brain tumour or caring for someone with a brain tumour is very challenging. Sometimes your Supportee may be having a particularly rough time for many reasons.

### HELPFUL TIPS:

- Acknowledge the value and courage of opening up – it's not easy
- Acknowledge and normalise your Supportee's feelings – let them know its ok to feel overwhelmed, sad, angry etc
- Remind them that feelings are not permanent and things change
- Share your own experiences of positive coping where appropriate
- Take care not to make assumptions or give advice. You are just joining with them in a shared experience, not telling them what to do
- Follow up - send an email, note, or text later that day or the next day to let them know you are thinking of them and wishing them well







**NOTES** \_\_\_\_\_

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## 4 Addressing different levels of need

**All Supportees will have varying past experiences, levels of resilience and existing supports in their life. They have requested support at this time, although will all be at different points in their journey with the brain tumour diagnosis and treatment. Each person's different needs will mean they require different levels of support.**

### HELPFUL TIPS:

- Accept that different Supportees will have different needs at different times
  - Some will want time-limited support – maybe one or two conversations
  - Others hope to start lasting friendships
  - Others may want to check in from time to time
- Supportees may have varying expectations about the Support Friend relationship and what it will involve. If you are unsure about expectations, ask how often they would like to communicate
- If you have concerns about what your Supportee is expecting from you, contact Brain Tumour Support NZ staff for guidance

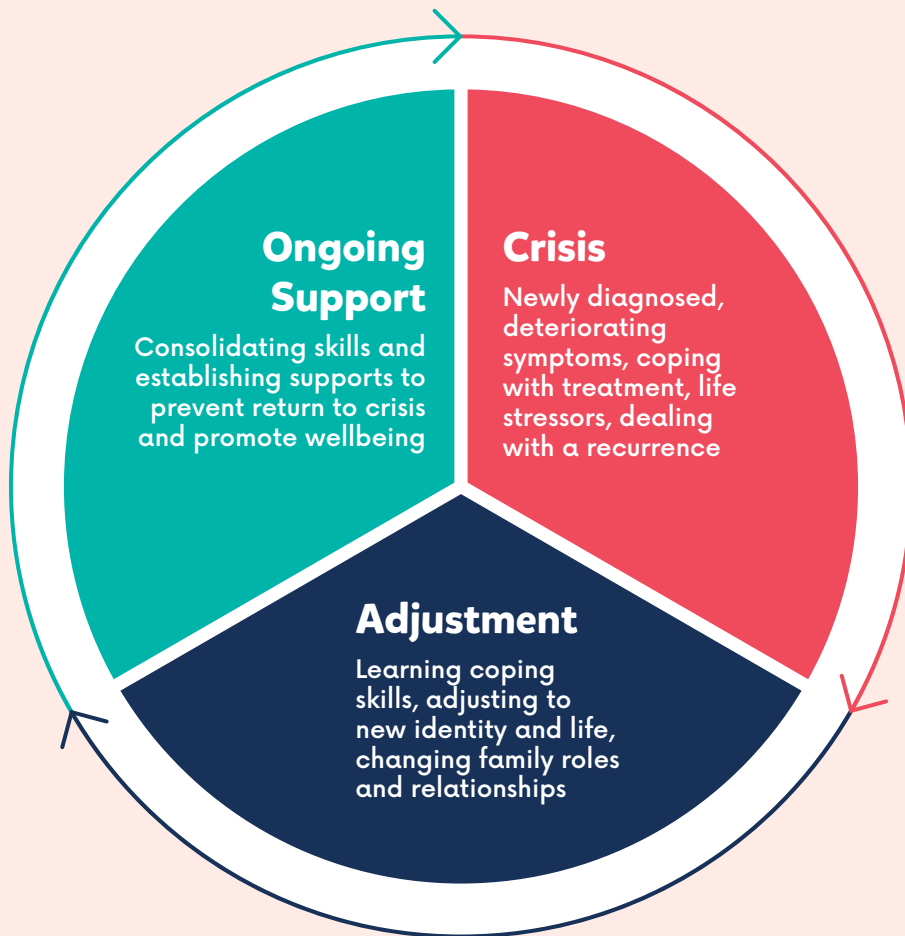


**TOP TIP!**

Be accepting of different needs at different times



## Your support role will differ depending on where your Supportee is in the adjustment cycle



**NOTES**

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## 5 Dealing with distressing feelings

**As a Support Friend you may have a variety of people you are supporting. You might encounter people who are angry, very sad, grieving or even suicidal.**

Some of the challenges you might face and suggestions for dealing with these are listed below.



### SADNESS OR DEPRESSION

Many Supportees will be sad, upset, or even crying. These are common reactions to a brain tumour diagnosis, treatment, or adjusting to a new life.

#### HELPFUL TIPS:

- Normalise - Remember it is common for a person affected by a brain tumour diagnosis to feel sad
- Listen and validate their feeling
- Relate with your own experiences where/when appropriate
- Sometimes sadness can progress to depression. If your Supportee's feelings seem to be overtaking their ability to function, suggest they contact their GP. Let BTSNZ know if you have serious concerns about their mental health.

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## TOP TIP!

**If you are unsure what to say, just listen and validate feelings**

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## ANGER

Anger can come in many forms and be directed in different ways. Even sad or depressed feelings can present as anger or irritability. Your Supportee may be angry at their diagnosis, their doctor, their family, or at the entire world. Anger is often about loss of control over one's health or life. It can also cover up other emotions such as sadness, grief, and fear.

### HELPFUL TIPS:

- If a Supportee is angry, allow them time to vent. Time spent with you may be the only safe space where they can do so (especially for caregivers)
- Relate where possible and share about healthy ways that you have coped with anger
- If a Supportee expresses anger toward you, it's probably not personal. However, if they are abusive toward you in any way, end the conversation and contact BTSNZ

## STRESS AND ANXIETY

It is common to feel anxiety in situations like undergoing a test or MRI scan, worrying about a recurrence, or dealing with life changes. Anxiety levels can vary greatly among people. Many find that their anxiety lessens by learning more about their diagnosis and treatment options.

### HELPFUL TIPS:

#### You can help with anxiety by:

- Talking about similar experiences when you felt anxious or stressed
- Sharing healthy ways that you cope with anxiety
- Encouraging Supportees to speak with their treatment team or contact BTSNZ to learn more about their brain tumour diagnosis and treatment options

## GRIEF

Patients and caregivers can experience grief during diagnosis, treatment, or recovery. Grief about loss of planned future, social and family roles, or abilities is common and normal.

Grief is complex and unique to each individual. There is no “right way” to do grief. It can take a long time to process all the feelings of loss associated with a devastating diagnosis.

### HELPFUL TIPS:

- Listen and acknowledge their feelings
- Sharing what you did to work through grief you’ve experienced
- Remind them that there is no right or wrong way to grieve, and that grieving takes time
- There are some excellent books about grieving if they are interested (see list on page 27).

## CHANGES RESULTING FROM THE BRAIN TUMOUR

Unique to brain tumour patients are the changes that happen in the brain due to the tumour itself, swelling, or treatment side effects. Some of these challenges may include memory loss, difficulty paying attention, or difficulty speaking. If your Supportee is a patient or survivor, they may not even be aware that these changes are occurring. If they are aware, they may feel embarrassed, frustrated, or grieving the loss of their prior ability.

Brain Tumour patients often experience more emotional reactivity and this is often most noticed by caregivers and loved ones. This can result in more extreme emotions in everyday life, potentially leading to verbal or physical aggression. While being more emotional is common, harm of any sort is never acceptable.

### HELPFUL TIPS:

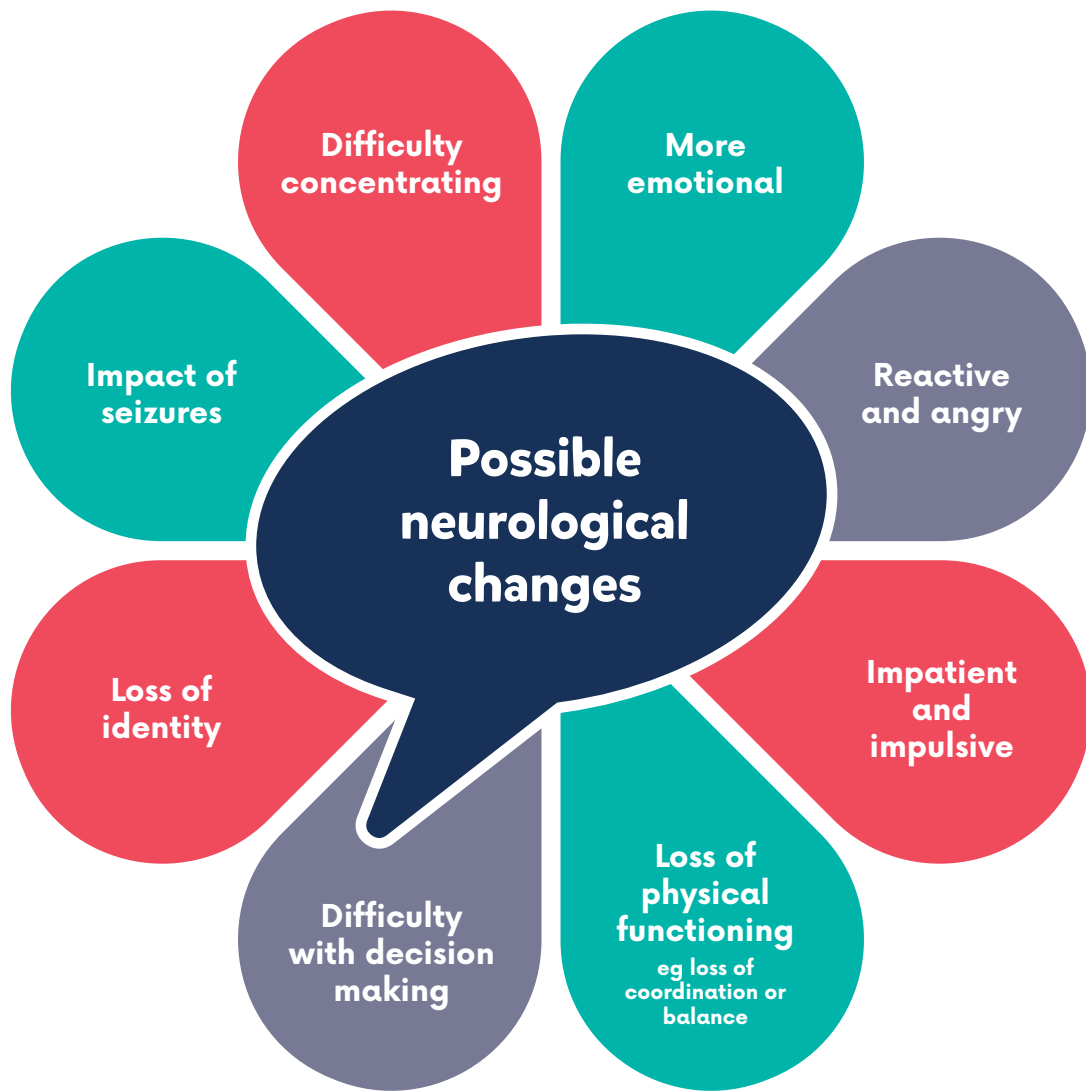
- Be patient and understanding of any difficulties being experienced
- Often just listening with a compassionate ear can help
- If you have experience around these challenges, share them with your Supportee

### IMPORTANT NOTE:

If you suspect your Supportee is exposed to or is being aggressive towards others –

- Ask if they feel safe (if they are a caregiver) or if they feel they might be at risk of harming someone else (if they are a patient)
- Keep calm and acknowledge what they are saying. Reassure them that it is common to be more emotional than usual but that harming someone else in any way is never OK
- If you are still worried, let them know you are concerned about safety. Let them know you will contact them back to discuss what supports might be helpful once you have consulted with BTSNZ
- Consult with the Support Friends Trainer for advice (contact details provided during training)





**Some of these distressing reactions can be triggering or challenging. Which feelings or responses might you find most difficult to deal with? Which tips would help you the most?**

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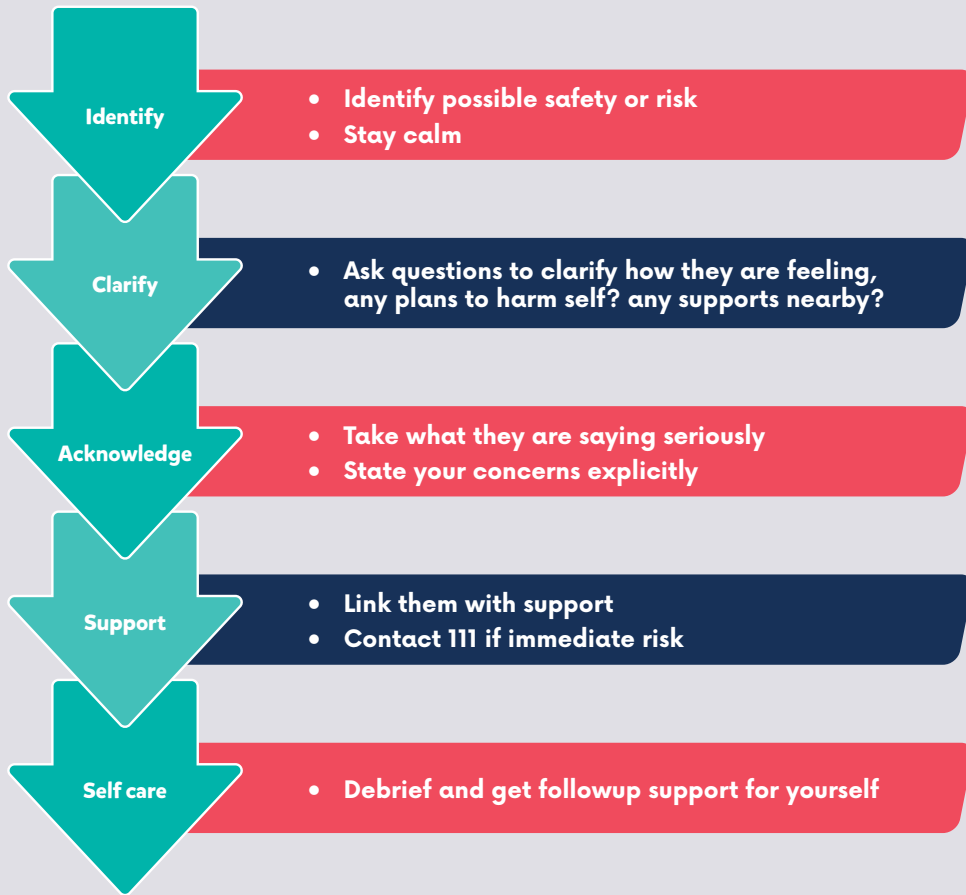
## 6 Risk and Suicidal Thinking

**As a Support Friend you are not expected to manage risk or suicidal thoughts in your Supportee. However, rarely you may find yourself seriously concerned about your Supportee's safety.**

### IMPORTANT STEPS IF YOU SUSPECT YOUR SUPPORTEE IS IN CRISIS AND/OR SUICIDAL

- **Recognise** when your Supportee is in crisis or is considering/planning to harm him/herself  
Examples - *"I want to give up on everything", "I wish I would fall asleep and never wake up", "Things are just too hard for me to continue"*
- **Keep calm** and use your active listening skills
- Take any mention of plans and thoughts seriously and **acknowledge these explicitly**  
*"It sounds like you are really struggling"*  
*"You seem to be feeling very low at the moment"*
- **Ask your Supportee** if you are unsure but suspect they are feeling suicidal  
*"Are you having thoughts of harming yourself?"*  
*"Do you have a plan to hurt yourself?"*
- **Be aware of the supports** you can guide your Supportee to access  
Encourage them to contact their GP to discuss how they are feeling  
Suggest they seek mental health support by calling Lifeline 0800 543 354
- If you feel that your Supportee is at **immediate risk**, call 111
- If you are concerned about someone's safety or are unsure about the risk or the best next steps, let your Supportee know you will consult with Brain Tumour Support NZ and will call them back shortly. Consult with the Support Friends Trainer for advice (contact details provided during training)





**Group Discussion:** What concerns or questions do you have about dealing with risk or safety?

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**Roleplay** – responding to a person in crisis

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**TOP TIP!**

Remember the boundaries and limitations of your role



## 7 Some pitfalls to watch for

There are no specific 'right' or 'wrong' ways to support someone who is struggling. However, there are a few things we strongly discourage as we know they are generally unhelpful or are against the values and philosophy of this programme.



### EXERCISE:

Take a few minutes to note down any specific things you think you will need to avoid. Share if you are comfortable to do so.

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**TOP TIP!**

**You are not on your own – reach out if you have questions!**

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## 8 Common Questions

### What do I do if my Supportee suddenly stops replying to my calls?

Supportees sometimes fail to respond to a Support Friend's first contact. Or, after communication has been established, Supportees sometimes suddenly stop responding to calls or emails.

This "drop off" can happen for a variety of reasons – they got the support they needed, they no longer feel the need for support or they didn't feel the 'fit' with you was ideal.

#### HELPFUL TIPS:

- Try again if you haven't had success from first contact attempt
- Allow them space if you already have been in contact. They may need some time for processing your last conversation
- Let them know by text or email that you are thinking of them and are available to support them whenever they are ready
- Please contact BTSNZ if you still have no success in making contact

### What if my Supportee needs professional help?

You are not a counsellor, mental health or medical professional. You cannot and should not address needs which require professional input. If your Supportee has needs which are beyond the role of a Support Friend, please contact BTSNZ.

These needs could include – mental health issues (e.g. major depression), caregiver burnout, relationship problems that started prior to diagnosis, seeking medical advice.

#### HELPFUL TIPS:

- If you believe that your Supportee is asking for more than you can offer, please be clear, kind, and direct with them. You can say, "I don't have experience with that," or "I can't help you with that. You'll need to speak with a healthcare professional."
- Let your Supportee know that you will consult with BTSNZ to find out the best supports to recommend and contact them back
- Consult with the Support Friends Trainer for advice (contact details provided during training)

**As a Support Friend, you may speak to someone who has a terminal diagnosis, or whose loved one may die. This can be distressing for both you and your Supportee.**

If you learn that your Supportee or their loved one is dying or has died, and you want support in addressing this, please contact BTSNZ for support. We can help you navigate these challenging situations.

**HELPFUL TIPS:**

- Accept that your own feelings relating to your personal journey may resurface when you are supporting someone else
- If you become overwhelmed in your experience as a Support Friend or you feel you can no longer be a Support Friend for any reason, that's okay. It is fine to take a break – just let BTSNZ staff know, and we can discuss next steps which could include returning to being a Support Friend when you feel the time is right
- It is fine for you to be both a Support Friend and a Supportee. BTSNZ is available to support everyone who needs help

**When should I contact the BTSNZ for help?**

- You feel your match with your Supportee is not working out
- You need emotional support
- You are finding it difficult to manage the complexity of concerns arising for your Supportee
- You are worried about your Supportee's risk or suicidal thoughts
- You find your Supportee's struggles difficult to address
- You need additional resources to share with your Supportee
- You want to refer your Supportee for professional support
- You have any other questions relating to your Support Friend role
- If you need to speak to someone regarding any of the above issues, contact your Support Friends Trainer

Please note that BTSNZ staff are not medical professionals, and that medical questions coming up for your Supportee should be addressed to their doctor.





## 9 Resources

### Important Contacts

- **Emergency** 111
- **Lifeline** 0800 543 354 or text Help to 4357
- **Youthline** 0800 376 633 or free text 234 or webchat
- **The Lowdown** Text 5626 (youth mental health)
- **Brain Tumour Support NZ** (027) 292-3337 or email us at hi@braintumoursupport.org.nz
- **Need to talk?** 1737 – free call or text any time for support from a trained counsellor
- **The Depression Helpline** 0800 111 757 or free text 4202
- **Healthline** 0800 611 116
- **Cancer Society** 0800 226237
- **Alcohol Drug Helpline** 0800 787 797
- **General information on mental health support in NZ** - <https://www.health.govt.nz/your-health/services-and-support/health-care-services/mental-health-services/mental-health-and-wellbeing-where-get-help>
- General information on suicidality
- <https://mentalhealth.org.nz/resources/resource/are-you-worried-someone-is-thinking-of-suicide>



### Useful Information on Brain Tumours and Supporting Others

- <https://www.braintumoursupport.org.nz/signs-and-symptoms>
- <https://tahuhikuroa.org.nz/>
- <https://www.lifeline.org.nz/suicide-prevention/help-for-others>
- **The Survival Guide for GBM** (Facebook Support Group)
- **American Brain Tumour Association** [www.abta.org](http://www.abta.org)
- **Neurological Foundation NZ** [www.neurological.org.nz](http://www.neurological.org.nz)



### Useful Books

- **Living with a Brain Tumour** by Peter Black
- **Glioblastoma - A guide for patients and loved ones** by Gideon Burrows
- **Resilient Grieving** by Lucy Hone
- **Grief Works** by Julia Samuel
- **This Too Shall Pass** by Julia Samuel
- **Brain Tumour Guide for the Newly Diagnosed** by Al Musella



## A special thank you

BTSNZ could not offer support to the Brain Tumour Community without you. We appreciate your willingness to devote time and energy to helping others. We thank you for offering your rare and valuable experience.

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## Acknowledgements

Brain Tumour Support NZ would like to thank the generous support of the American Brain Tumour Association (ABTA) in sharing resources and expertise towards the development of this Handbook.

Get in touch for more information

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