

SUPPORTING MENTAL WELLBEING:

A guide for ALS Patient Organisation Leaders





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How to use this booklet:

The booklet is divided into five sections, each designed to be read independently.

It is provided as an interactive PDF:

- The Contents page acts as a navigation menu, click any item to jump directly to that section
- The Home icon on each page will take you back to the Contents page

Each section offers specific guidance, so you may choose to print individual sections for home or office use.



Dear Reader,

As patient leaders, advocates, and volunteers, we provide vital emotional support to everyone affected by ALS (Amyotrophic Lateral Sclerosis). Our commitment makes a real difference to PALS and CALS, but it can also come with emotional challenges and moments of uncertainty.

When faced with someone in emotional distress, we may find ourselves unsure of how to respond or worry about saying the wrong thing. Many of us find ourselves in similar situations, and it's normal to feel uncertain about how best to respond, especially when we are not trained counsellors. It can also be difficult to take the time to look after our own emotional wellbeing when constantly having to provide support to people who are emotionally distressed.

This handbook has been created to provide practical tips and guidance to help us feel more confident in meeting the emotional needs of people affected by ALS. It also explores ways we can look after our own emotional wellbeing and that of others who work in our organisations.

The guidance included in this booklet was developed by Kym Winter, a leading psychotherapist with extensive experience in rare diseases and Chief Clinical Officer and Founder of Rareminds, a UK-based charity providing specialist counselling services for rare disease communities. This content was first presented during two interactive webinars that EUpALS was pleased to organise and host in October 2025 with the unconditional support of our industry partner Zambon.

We are delighted to now make this valuable resource available to the wider ALS community.

Whether you are new to patient leadership or have years of experience, we hope this handbook serves as a practical companion in your important work.

With warm regards,

Evvy Reviers
Chairwoman, EUpALS





Mental health and wellbeing in ALS

People impacted by ALS/MND* face complex challenges to their mental health and wellbeing.

Some of these occur at the point of diagnosis given the emotional impact of life-changing news. Others occur over time as the disease progresses.

Worries about the future (including dying), financial concerns, frustration, low mood, despair, grief and caregiver stress are very common. ALS can also impact neurologically on mental health by affecting emotional stability, cognitive capacities, and personality.

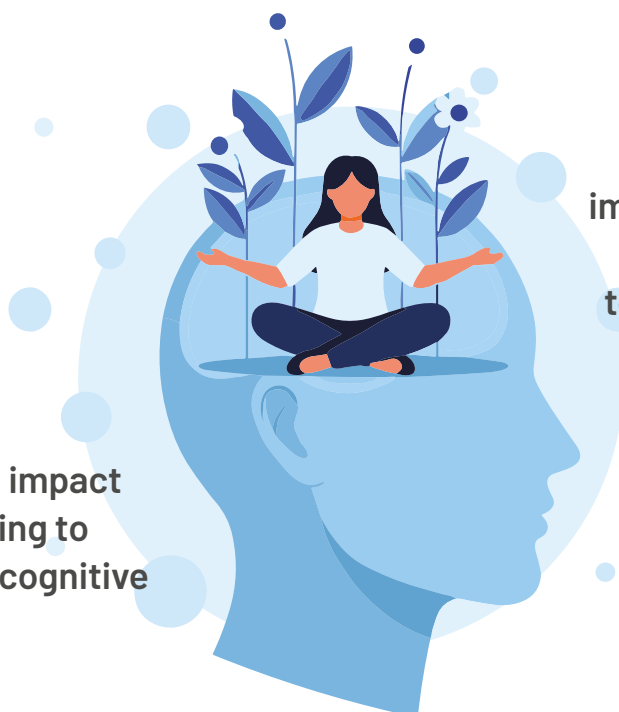
Living with the wide-ranging impact of ALS can also place considerable stress on the relationships between affected persons, partner-carers, and other family members too.

WHY DOES MENTAL HEALTH MATTER?

Physical health needs often get prioritised by individuals, organisations and healthcare professionals alike.

However, this can mean that mental health and wellbeing needs get overlooked.

Poor physical health can impact on mental health by leading to depression, anxiety and cognitive decline.



Poor mental health can impact on physical health and the capacity to self-care, be resilient, and use coping skills.

*In some countries, ALS is called Motor Neuron Disease (MND). To keep things simple and clear, we have used the term ALS throughout this booklet.



Mental health and wellbeing are dynamic states that exist on a continuum. They include emotional, psychological and social wellbeing. The capacity to cope with the impact of an ALS diagnosis is very personal.

YOUR ROLE AS AN ORGANISATION

Raising awareness of ALS's impact on mental health and wellbeing for both affected persons and family members – and ways to help manage this – supports everyone to speak more openly about their own mental health and wellbeing.

This guide is to support you in doing this. It includes the importance of looking after your own mental wellbeing as a Leader whilst you are doing this too.

1

Supporting your community's mental wellbeing





Patient organisations play an invaluable role in supporting mental health and wellbeing.

They do this through providing:

IMPLICIT SUPPORT	EXPLICIT SUPPORT
Sharing experiences, which eases isolation	Speaking openly and directly about mental health, which reduces stigma
Providing information, which mitigates stress and uncertainty	Raising awareness of common challenges to mental health and wellbeing, and information to help address these
Supporting relationships, which strengthens belonging	Encouraging healthcare professionals and policymakers to integrate mental health considerations into care and treatment protocols
	Appropriate signposting, and developing trusted resources
	Providing thematic, targeted support and provision e.g., psycho-educational resources or talks/events on coping with stress, dealing with diagnosis, relationships, etc.

It can be helpful to read through the below to consider what type of support your organisation provides already. You can also use it to think about what you would like to provide in time.

YOUR ORGANISATION EXISTS!

Do not underestimate how this alone helps support mental wellbeing.

Even if someone impacted by ALS never engages directly, just knowing your organisation exists *itself* provides reassurance. That you exist at all is the **single most important thing** that you do to support mental wellbeing.

GUIDES TO MANAGING COMMON PRACTICAL PROBLEMS

Easy-to-read online information with practical advice on managing a range of common difficulties can help reduce both anxiety and stress, e.g., coping with financial concerns, talking to your employer, or accessing mobility aids.



Consider providing these in a range of formats too e.g., written word, video, audio, or in languages that are most common in your own country.

TALKS AND INFORMATION ON MENTAL HEALTH AND WELLBEING

Many people still feel ashamed about 'not coping' as well as they would like. This helps normalise talking about challenges to mental health and wellbeing, and reduce stigma. These might include:



talks on the mental health impact of ALS, and sources of support



information about carer wellbeing, and sources of support



newsletter articles and information



social media posts on mental wellbeing



'quiet spaces' at events, conferences, etc. for people to access if they need to

AN ORGANISATIONAL STRATEGY FOR MENTAL WELLBEING SUPPORT THAT CAN DEVELOP OVER TIME

This might include developing:

Peer-based support such as

- Social media based support groups/forums (separate ones for affected persons and caregivers tend to allow people to speak more freely)
- Online or in-person support groups that meet on a regular basis
- Telephone support, or helplines
- Mentoring or buddy schemes

Professional support such as counsellors, or support workers. Funding is not always easy to obtain, but collaborative projects can meet funding criteria more readily.

Consider appointing a 'mental health trustee' with suitable expertise to help collate resources, build protocols for risk management and safeguarding, and support you as a Leader.





REMEMBER!

Some cultures or communities attach more stigma to talking about mental health than others. Consider how to build resources that are culturally relevant and sensitive, according to your own country's demographic.

ADVOCATE FOR THE INCLUSION OF MENTAL HEALTH AND WELLBEING PROVISION, AND PSYCHOLOGICALLY INFORMED CARE.

Contributing to discussions about national policy, clinic services, treatments and trials (or supporting others to do so) helps embed mental health and wellbeing into ALS care through:

- healthcare professionals, and clinics
- government policy
- health and social care systems
- commissioning bodies
- your own organisation's funders, and trustees

I had nothing else in common with them really. But that didn't matter. All I needed to know was that they were there and we were all doing it every single day, coping with the nightmare of living with this condition and what it meant.
(Support group member)

Talking to the counsellor really helped. They were able to help me realise that although the way [husband] was coping was difficult for me, it was not totally unexpected.
(Support group member)



What is 'psychologically informed healthcare'?

It involves:



the direct provision of
mental health support
and services in clinics, etc.



sensitive, empathic
interactions with
professionals



considering how clinics
and services are
designed and run



REMEMBER!

Your role as a patient advocacy organisation is to complement and advocate for statutory support for mental health and wellbeing for ALS patients and families, not replace it.



2

Active listening





Someone contacting your organisation will usually be looking for advice, support or both. What everyone needs at that point of engagement is to be actively listened to. 'Active listening' allows you to work out most effectively what type of help they might need as an individual at that particular moment in time.

For some people, **the most important thing** could be just being listened to by someone who understands what they are going through.

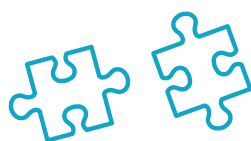
Active listening aims to:



- **understand** the speaker's perspective, without judgement



- **communicate** that understanding back to the speaker



- **allow** the speaker to confirm or correct the accuracy of your understanding, and/or refine and add additional information if they wish



Our culture means it can feel more acceptable to ask for advice, than to be listened to.

Some people may contact your organisation saying they are looking for advice, but what they may really be wanting is to have their experience acknowledged and heard.



ACTIVE LISTENING: USING YOUR EARS!

EARS is a great acronym to help you have supportive and effective conversations.

Engage in conversation

Use their name, open up a conversation, empathise.

“*I can understand this is very upsetting, (name). How are you coping?*”

Refer to Resources

Make sure that the person knows what resources are available. These might be within your organisation such as information sheets, support groups, etc. or others e.g., other charities, healthcare organisations, etc.

“*Did you know we run an online support group, (name)? How would you feel about coming along OR have you tried it at all?*”

“*I also have a factsheet I can send you about this. Would that be ok?*”

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Actively listen

Validate experience, and encourage talking. Use open questions.

“*I can hear how upset you are. Can you let me know more about what's causing that?*”

“*It sounds like you've had a really difficult time. How are you at the moment?*”



REMEMBER!

Open questions are ones that do not invite just a 'yes or no' answer.

Signpost and Speak again

Sometimes you might want to suggest contacting another person or organisation for additional support.

“*I found it really helpful talking to a counsellor when my mum got ill. How would you feel about doing that? (Follow up with details of how to do this)*”

“*I'm not sure we are the best organisation to help you with that aspect, but I know (name of organisation/person) are very good on this. Can I send you their details/have you had any contact with them?*”



If you are worried about someone, or want to provide more support or information at a later date, arrange to speak again. Make a specific day and time if possible.

“ *I'd really like to know how you get on. Would it be ok if I gave you a call next week on (negotiate a specific day and time to call. Make a note in your own calendar)?*

CRISIS SUPPORT

Make sure members know that it is ok to use Helplines and Crisis Lines. Post these on your website, and as occasional information elsewhere e.g., social media, newsletters, etc.

SENSITIVE SIGNPOSTING

Support for mental health and wellbeing can vary widely, and one size does not fit all!

It can include:

- psychology services
- online support forums
- peer-led support
- family therapy
- psycho-educational resources
- medication
- counselling
- buddy schemes
- mentoring
- workshops, and group programmes

Signposting to specific groups e.g., LGBTQI+, carers, older people, by ethnicity/culture, young people, etc. can feel more accessible for some people, and help ease isolation too.



WHEN MIGHT MORE PROFESSIONAL HELP BE NEEDED?

We often turn first to family, friends, or people going through something similar when we are trying to cope with, and make sense of, difficulties in life. A patient organisation can be part of this.

However, there will be times when talking to a professional like a psychologist, counsellor or psychiatrist can also be very helpful.

These might include:

- persistent low mood, hopelessness or despair
- prolonged anxiety or distress
- making repeated contact in acute distress
- decline in mental wellbeing such as self-neglect, isolation, apathy
- changes to personality
- worrying behaviour e.g., self-harm, violence, etc.
- confusion, or thoughts that do not seem based in reality
- suicidal thoughts, or thoughts about assisted dying



When signposting for mental wellbeing, it is important to do so in a way that feels supportive, and non-judgemental.

This means taking into account the type of support that individual might find acceptable personally, culturally and practically.



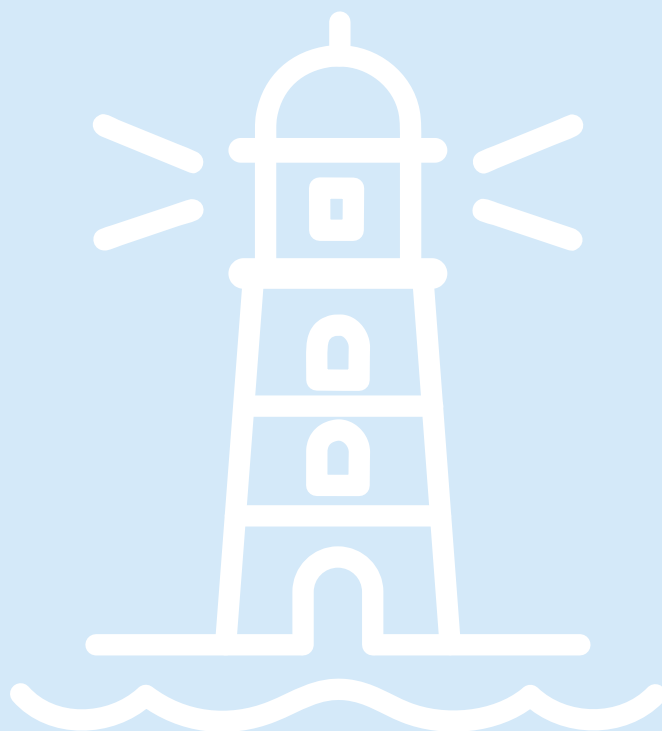
When someone contacts you for support, THINK:

- *What is this person contacting me for?*
- *What support do they need right now?*
- *What can the organisation provide?*
- *What can I provide?*
- *What sort of additional (external) support might be needed?*



3

Managing a mental health crisis





A mental health crisis often refers to when someone's life could be at risk e.g., having suicidal thoughts.

It can also refer to when a person's mental health is 'breaking down'. They might then seem confused, disengaged from reality, or show little insight into how they might be impacting other people.

It may not always be clear if someone is in crisis. However, you might feel concerned or anxious when talking with them.



Notice 'red-flag' phrases like:

- *I can't go on like this*
- *I just want to die*
- *My life has no meaning anymore, I just want to stop*

You will not make it worse if you ask someone directly about (for example) if they have been feeling suicidal.

“ *You seem to be really struggling [name]. I hope it is ok to ask, but I am wondering if you have been thinking about taking your own life?* ”

However they respond, it is a valuable opportunity to offer some signposting to additional support.

CONFIDENTIALITY: RISK TO LIFE, OR SAFEGUARDING CONCERNS

Sometimes, a person may share something that is very worrying about themselves, or another person. They may ask you not to tell anyone else.

If there is a risk to life, or a safeguarding issue, you cannot promise this. Let them know gently that you may have to share what they tell you with another person, in order for you to help them access support or keep safe.

Make sure that your organisation has clear processes in place for situations like this. It should include an experienced colleague or professional to liaise with.



IF SOMEONE IS STRUGGLING WITH THEIR MENTAL HEALTH

Acknowledge to them that they seem very distressed, or struggling.

Say that you would like to help them access some support.



Debrief with a friend or colleague.

Think through together whether any further action is needed, and have support available for the emotional impact on yourself.



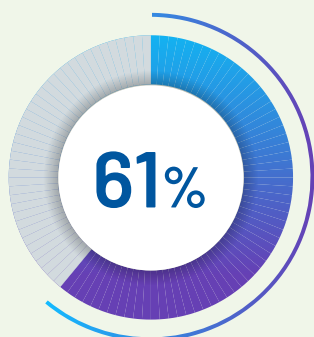
4

Looking after your own mental wellbeing





Running a patient organisation can be rewarding, but very demanding.



61% of rare leaders were concerned about maintaining boundaries and how to 'step back' to self-care

(Rareminds Matter Survey 2024)

<https://www.rareminds.org/wp-content/uploads/2024/04/RaremindsMatterSurveyReport.pdf>

WE CAN ONLY SUPPORT OTHERS IF WE FEEL SUPPORTED TOO

It's important to build in support for yourself as a leader. This might be:

Personal:	Organisational:
Talking to trusted family and friends about the 'ups and down' of your role	Training and supervision for front-line support staff
Making time for your own self-care and personal responsibilities	Having an organisational mental wellbeing policy for staff/volunteers
Building supportive relationships with other ALS Leaders, or support staff/volunteers	

You cannot pour from an empty jug!



DRAWING ON LIVED EXPERIENCE

Lived experience can be very powerful. It means you can respond to someone with empathy by drawing on similar situations from your own life. However, it means that the emotions associated with your memories might sometimes resurface too.



If this feels difficult at all, make sure that you treat yourself gently afterwards. Consider talking with someone you trust. This could be a friend, or a professional.



Be careful not to always assume that your own experience or feelings are exactly the same as someone else's. We are all individuals who cope as best we can in different ways at different times.

MANAGING YOUR WORK-LIFE BALANCE

This is essential to be able to cope with the demands of your role over time. Here are some ideas to help you manage your time and energy effectively.

1. Time management

Think about how much of your time you can make available to your work as a Leader. Ask yourself: How much time **can** you make available, and do you **want** to make available? Start to make clear decisions about how many hours a week you can give, and also **when** you want to make these available.

*I find it really hard sometimes juggling my family, work and my organisation's needs too. You want to be there for everyone, but you have to take a step back now and then to 'reset'.
(Community Leader)*

*When I accepted I just couldn't do everything, I got much better at deciding what I was and wasn't going to do each day. That meant I had to ask for help, or say no. It wasn't easy, but I'm not drowning anymore!
(Community Leader)*



2. Use technology wisely

- Social media is a time sponge! Allocate time each day to check or post
- If you moderate a Facebook group, post crisis lines and hours of moderation at the top
- Use your email signature to indicate the days/hours you are available. Use 'Out of Office' to create space to work on tasks that need focus

3. Use voicemail to manage calls

- You cannot be available all the time
- Have a clear, friendly message that indicates they can leave a message, that you will call back as soon as possible, and your 'working hours'
- Do not promise availability that you cannot meet
- Have a script ready if you need to defer, or end, a call to attend to something else

I can hear this is really important. I can't give you my full attention right now and I'd really like to. Could we find a time when I can call you back?

4. Create a dedicated workspace

- If you do not have a physical office, create a 'virtual' one. Try to only do your organisation's work there
- Have a separate work email
- Dedicate a small area in your home which is where you 'go to work'
- Try a virtual commute or small ritual for that space e.g., walk around your house/ outside for a few moments to signify starting and finishing

5. Manage expectations - yours and other people's!

As a rare leader you are naturally inclined to want to 'do the impossible!' That is a great quality but can also lead to burn-out.

Consider:

- Taking any project time-frame - and double it!
- Don't over-promise with respect to your availability, or capacity
- Beware the 'passion goggles!' It's very easy to get caught up in a project that you may not have the time or resources to really commit to (even if you'd like to!)



- Press 'pause' if you feel under pressure by someone, or anxious. Ask for time to come back to it
- Learn to negotiate (e.g., *I cannot do X right now, but I could do Y. How would that sound?*)

6. Build your own personal 'support community'.

Having encouragement and support from others is really important, especially as rare leaders often work in isolation.

- Find other ALS or rare leaders that you know and like. Start informal support groups, sounding boards, buddy systems, etc.
- Use EUpALS and its member network for advice, sharing information and networking
- Maintain your 'non-rare' support networks and friendships
- Build leadership support and development for yourself (and others) into your organisational strategy e.g., mentoring, training, supervision/coaching
- Recruit Trustees with expertise in mental health to not only help develop community resources, but support you in your role too



REMEMBER!

Finding the right 'work-life' balance for you is always a work in progress!

I did a short course on patient advocacy leadership. Five of us swopped our contact details afterwards. It's been great to have them to check things out with, share advice, have a moan!
(Community Leader)

Realising I didn't have to respond to everyone right away was a game-changer for me!
(Community Leader)

5

Contacts and resources



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[illegible]



Also list out below any information and resources you find regarding mental health and wellbeing. It could be ALS specific, or more general.

You may want to share some of it with your community, some may be for your own learning and support. We've included a few already.

Rareminds Wellbeing Hub

Rareminds provides specialist mental health and wellbeing support for people impacted by rare, genetic and undiagnosed conditions. It has a freely accessible Wellbeing Hub that is being translated into different languages. The Hub includes a range of informational resources such as dealing with diagnosis, managing difficult feelings, coping with change, grief and loss, etc.

<https://www.rareminds.org/wellbeing-hub/>

www.rareminds.org



EURORDIS

EURORDIS (European Organisation for Rare Diseases) is an alliance of over 1000 rare disease patient organisations from 74 countries. It provides resources for leaders including information on living with a rare condition and its impact on mental health and wellbeing. They also offer a Mental Wellbeing Toolkit to help you design and build resources for your community.

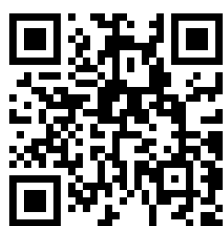
<https://mhtoolkit.eurordis.org/>

www.eurordis.org



EUpALS

als.eu has a network of members who are patient organisations across Europe. Contact info@als.eu for further details.



<https://als.eu/>

Befrienders International

Befrienders is an international organisation that provides crisis line details according to country.



www.befrienders.org



Mental Health for the Rare Disease Community

The guidance included in this booklet was developed by Kym Winter, a leading psychotherapist with extensive experience in rare diseases and Chief Clinical Officer and Founder of Rareminds, a UK-based charity providing specialist counselling services for rare disease communities. This content was first presented during two interactive webinars that EUpALS was pleased to organise and host in October 2025.

Disclaimer: Information contained within this resource is not intended to substitute for personalised medical advice, or mental health intervention. All quotes used are taken from Rareminds' own feedback via workshops, talks and events and used with permission.

EUpALS would like to thank Zambon Biotech for its unconditional support of this project.

