



MY
creative
LIFE

**A self management tool for people
with long-term conditions**

PRACTITIONER HANDBOOK

www.mylifetool.co.uk

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INTRODUCTION TO THE PROGRAMME

MyCreativeLife is a seven-session programme which uses creative activities to support people to reflect on how they self-manage their long-term condition(s). The programme has been developed in partnership with people with long-term conditions and practitioner psychologists.

People with a range of long-term conditions, including diabetes, asthma, depression, anxiety, hypertension and epilepsy, have taken part in the programme and reported positive effects on their self-management experience and wellbeing.

We know that engaging in creative activities can be beneficial to well-being¹ and that they are used as self-management strategies.

The MyCreativeLife programme uses specific creative activities that we have designed in partnership with people with long-term conditions that encourage and support reflection on different elements of the self-management experience. In this way, our programme utilises the problem-solving², contemplative¹ and self-developmental¹ aspects of creativity to support people with long-term conditions to actively reflect upon their self-management experience and identify and work through strategies that are beneficial to them and which fit within the context of their lives.

MYLIFE TOOL

The MyCreativeLife programme has been developed in conjunction with MyLifeTool.

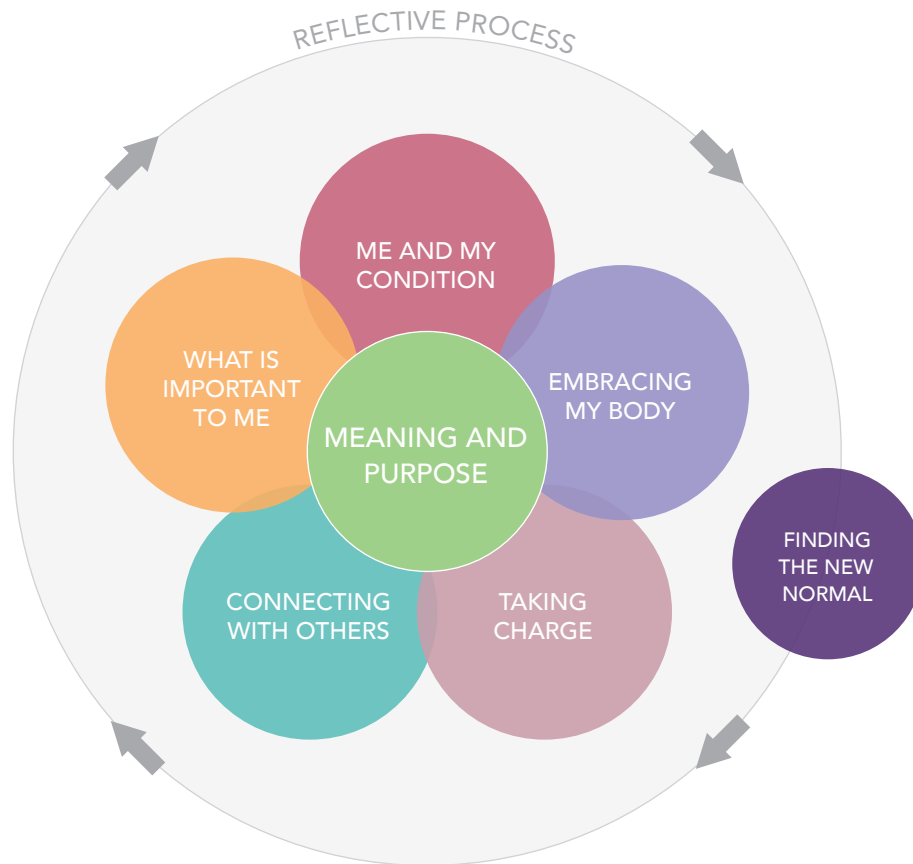
Each session focuses on an area of self-management considered in the MyLifeTool toolbox. Part of MyLifeTool is a scrapbook where people can reflect on their day-to-day life and experience of self-management. We believe that using the scrapbook as a creative space to reflect on experiences can help people to identify and explore self-management strategies that work for them. The concept of scrapbooking and reflection through creative activity then formed the basis for the MyCreativeLife programme.

¹ Fancourt, D., Garnett, C., Spiro, N., West, R. & Mullensiefen, D. (2019) How do artistic creative activities regulate our emotions? Validation of the Emotion Regulation Strategies for Artistic Creative Activities Scale (ERS-ACA). PLoS ONE 14 (2). DOI: 10.1371/journal.pone.0211362

² Gardner, H. (1982). Art, mind and brain: A cognitive approach to creativity. New York: Basic Books Inc.



OUR SELF-MANAGEMENT FRAMEWORK



We see self-management as a journey towards finding or maintaining meaning and purpose in life.

It is an ongoing process that people approach from their own perspective, to fit with their life, aims and needs; finding the new normal in the midst of changes in their condition and circumstances.

We therefore believe that reflection is a key aspect of self-management which encourages people to learn about their own form of the condition and its implications for them in the context of their lives.

Our self-management framework was developed through research exploring the lived experience of self-managing a neurological condition³. We used the five elements of self-management to develop MyLifeTool and the MyCreativeLife programme and apply the framework to long-term conditions in general.

Me and my condition: coming to terms with how the condition may affect their identity and their expectations of themselves.

Embracing my body: paying attention to what their body is telling them; exploring planning and pacing techniques to conserve energy levels.

Taking charge: learning about their own experience of the condition, their limits and strengths, how to make the most of good days and develop resilience to deal with bad days.

Connecting with others: support from people who understand what they are going through and giving support to others.

What is important to me: finding what gives them purpose in life, such as spending time with family, setting themselves challenges and goals.

³ Kiling, S., Erdem, H., Healey, R., & Cole, J. (2020). "Finding meaning and purpose": A framework for the self-management of neurological conditions. *Disability and Rehabilitation*. DOI: 10.1080/09638288.2020.1764115



DELIVERING THE PROGRAMME

This is a group programme which is divided into seven sessions. Sessions one and seven explore the self-management journeys of group members prior to starting the programme, during the programme and moving forward. Sessions two to six focus on a specific element of the self-management framework/booklet from MyLifeTool.

Each session focuses on a specific creative activity designed to encourage reflection and discussion. The session can begin with a brief (up to ten minute) discussion of the associated MyLifeTool booklet and the group spends the remainder of the session working on the creative activity. We have provided templates for each activity and information sheets which you may wish to circulate to the group in advance of each session; some people may wish to use these and others may not. We have provided two different activities for sessions two to six. You may choose to give people in the group the choice of activity or you may choose one to focus on.

The scrapbook

Everyone in the group should either be given or asked to bring along a scrapbook that they can work on throughout the programme to aid reflection. An A4 blank book is suitable. They can use the scrapbook to work on the creative activities each week but they should also be encouraged to build the scrapbook outside of sessions. The scrapbook can include words, images, photographs or anything else that represents their self-management journey. They may even use it like a diary if they prefer.

Length of the sessions

It is advisable that sessions last between 90 minutes and two hours, with a short break half-way through. It can be difficult for people to engage with the activity and engage in meaningful reflection in just a one hour session.

Length of the programme

Sessions can take place every two weeks. This gives people time to reflect work on their scrapbook and engage with the activities in MyLifeTool in between sessions. However, running weekly sessions may also be appropriate.

Although the programme is designed as seven sessions, you may choose to run it as a rolling programme by repeating sessions two to six and running session seven as required. Two activities have been provided for sessions two to five and you can find activity sheets online which are short creative activities linked to each of the MyLifeTool booklets. We continually add new activity sheets so do check from time to time for new activities.

Resources

- Crafting materials (coloured pens, pencils, card, beads, stickers, magazines, textiles, etc).
- Scrapbook
- Activity templates (and information sheets)
- MyLifeTool (available online at www.mylifetool.co.uk)





GUIDING PRINCIPLES

Foster reflection and discussion

MyCreativeLife is designed as a group programme and the activities in each session have been designed to initiate discussion around the self-management experience. It is these conversations, where people share their ideas and experiences of self-management with each other, that support and encourages reflection. The role of the practitioner should be as minimal as possible, although they may need to be more involved in initiating discussion in the earlier sessions while the group dynamic is being established.

Everyone can be creative

It is important that people are not discouraged by the creative element. We all have the capacity for creativity and creativity comes in many different forms. We have provided templates to support people who are concerned that they are not very creative. They can use words, rather than images, like inspirational words or phrases, song lyrics or poems they have read. Others might work with cuttings from magazines, or even take their own photographs. The practitioner may need to work with some people to identify creative activities that suit them.

Non-instructional

The aim of the programme is to foster a safe, reflective space. It is not intended to promote specific self-management activities or strategies. People should be given the reflective space to explore their own self-management experiences and learn to understand their own particular experiences of their condition(s). However, they may share strategies which they have found beneficial and other members of the group may choose to try these for themselves.

Some people may come to the session with their own creative activity in mind. This can be the case for those who regularly engage in creative activities. They should not be discouraged from doing their activity but they should be encouraged to engage in the discussion.

Peer support

The programme is at its best when the group works together to discuss and reflect upon their self-management experience. We have outlined how each of the activities can be completed as a group if the group wants to do this.

Peer mentors can also be involved in the sessions to facilitate discussion. We recommend two to three peer mentors per group. The practitioner/host organisation must ensure that they are appropriately trained and have DBS checks in place.

The practitioner must always be present in the sessions and should offer debrief sessions for the peer mentors.





LEADING THE PROGRAMME

For the following reasons, it is important that the practitioner has relevant experience of facilitating group support sessions:

- The practitioner must ensure that the group remains a safe space for people to discuss their experiences and challenges. We also recommend that groups are closed and not open to new members after the first session, to help develop a group dynamic and create a comfortable space for group members to share their experiences.
- This is not a therapeutic programme and if it becomes evident that some people require more therapeutic or psychological support, perhaps in adjusting to their condition, for example, the practitioner must be prepared to refer them to relevant support services.
- It is advisable that practitioners build in at least ten to fifteen minutes at the end of each session for people to approach them with any queries or concerns they may have.

We recommend that practitioners hold at least a level three qualification or have equivalent relevant experience. It is the responsibility of the organisation/practitioner to ensure that the programme lead and peer mentors (if they choose to include them in the programme) are appropriately qualified, trained and supported.

This programme is not an alternative to medical advice or intervention. Group members should be made aware of this and advised to speak to a relevant healthcare professional about issues or concerns related specifically to their condition.

Online delivery

The programme can be delivered face to face and online. If working online, the organisation/practitioner must ensure that the platform they use is secure. They must also make it clear to the group that the sessions must not be recorded.

The activity templates and information sheets are particularly useful for online delivery. Clients do not need access to a range of crafting materials for the online sessions; coloured pencils/pens and an A4 scrapbook are sufficient.





PROGRAMME STRUCTURE

<p>SESSION ONE: MY JOURNEY</p>	<p>ACTIVITY: My Vision board</p>
<p>SESSION TWO: ME AND MY CONDITION</p>	<p>ACTIVITY: My ID badge ACTIVITY: My Shield</p>
<p>SESSION THREE: EMBRACING MY BODY</p>	<p>ACTIVITY: Listening to my body ACTIVITY: My pacing journey</p>
<p>SESSION FOUR: TAKING CHARGE</p>	<p>ACTIVITY: My aims ACTIVITY: My strengths tree</p>
<p>SESSION FIVE: CONNECTING WITH OTHERS</p>	<p>ACTIVITY: My social system ACTIVITY: Message in a bottle</p>
<p>SESSION SIX: WHAT IS IMPORTANT TO ME</p>	<p>ACTIVITY: Finding time for me ACTIVITY: Thank you card</p>
<p>SESSION SEVEN: MY JOURNEY</p>	<p>ACTIVITY: My Vision board</p>





This is an introductory session to introduce the group to the programme and MyLifeTool. You can take some time to explain how the tool works and explore each booklet briefly. Group members should be encouraged to work through the booklets in their own time and in the order that suits their needs but each week you will focus on a specific booklet during the sessions. You should also introduce group members to the scrapbook and explain that they can work on this both within and outside of sessions.

The rest of this session will explore their self-management journey. The “My Journey” booklet in MyLifeTool focuses on this and you can use this booklet to support this session if you wish. It is important to encourage the group to think about where they are in their self-management journey and what they want to achieve from taking part in the MyCreativeLife programme. The creative activity is designed to support this and the group will return to this activity in the final week of the programme to reassess where they are in their journey and their next steps.

SUGGESTED ACTIVITY: My Vision board

To support discussions of the group’s expectations of the programme and what they hope to achieve by taking part in the programme, they can be guided to design their own vision board which represents who they are, their interests, hopes, the self-management activities they have tried previously and the ones they find useful.

They might also want to think about the different elements of self-management: how they see themselves; how aware they are of their physical symptoms and pacing themselves; how

much they understand their own experience of their condition, use their strengths to their advantage and how resilient they are; how their social connections support them in their self-management journey; which activities give them a sense of purpose and how well they manage to find time for themselves. People can use words/phrases, cuttings, images, drawings; anything that represents their journey and where they want to head by taking part in the programme.

As a group: the group can produce a large-scale vision board that represents what each person brings to the group, their expectations of the programme and where they want to head by taking part in the programme.





MY VISION BOARD

The form consists of several empty shapes for a vision board. On the left, there is a vertical column of four circles. To the right of the circles is a large empty rectangle. Further right is a smaller empty rectangle. Below the large rectangle is a rectangle containing four horizontal lines for writing. At the bottom left is a rectangle with four small grey dots in a vertical column. At the bottom center is a large empty rectangle. To its right is another empty rectangle.



This session supports people to reflect on who they are, what their values and expectations of themselves are and how they want other people to see them. The activities focus on a person's sense of self in light of their condition(s) and managing the expectations they place on themselves. They serve as a way to start conversations about the importance of being kind to yourself and recognising your strengths and achievements. People who are not confident in their creative skills may prefer to write inspirational words or phrases in these templates.

You should be mindful that some people will have negative images of themselves, may try to hide their condition from others or have unrealistic expectations of themselves. These issues can be explored but if you are concerned that there are underlying psychological problems that require more therapeutic support, you should be prepared to refer the person appropriately.

SUGGESTED ACTIVITY A: My ID badge

Group members can create their own ID badge and lanyard using words or images that represent how they see themselves and how they want others to see them. They can be guided to think about their different roles, like being a parent, a partner, a student, a worker, etc. and how they manage these roles alongside their condition(s). They might also consider their values and what is important to them, like honesty, trust, etc. For example, someone might value being there for other people but their condition may interfere with this, so encourage them to explore other ways they can be there for others.

As a group: use a larger copy of the template and work as a group to create an ID badge for a person with a long-term condition. Consider what they would like others to know about being a person with a long-term condition.

SUGGESTED ACTIVITY B: My Shield

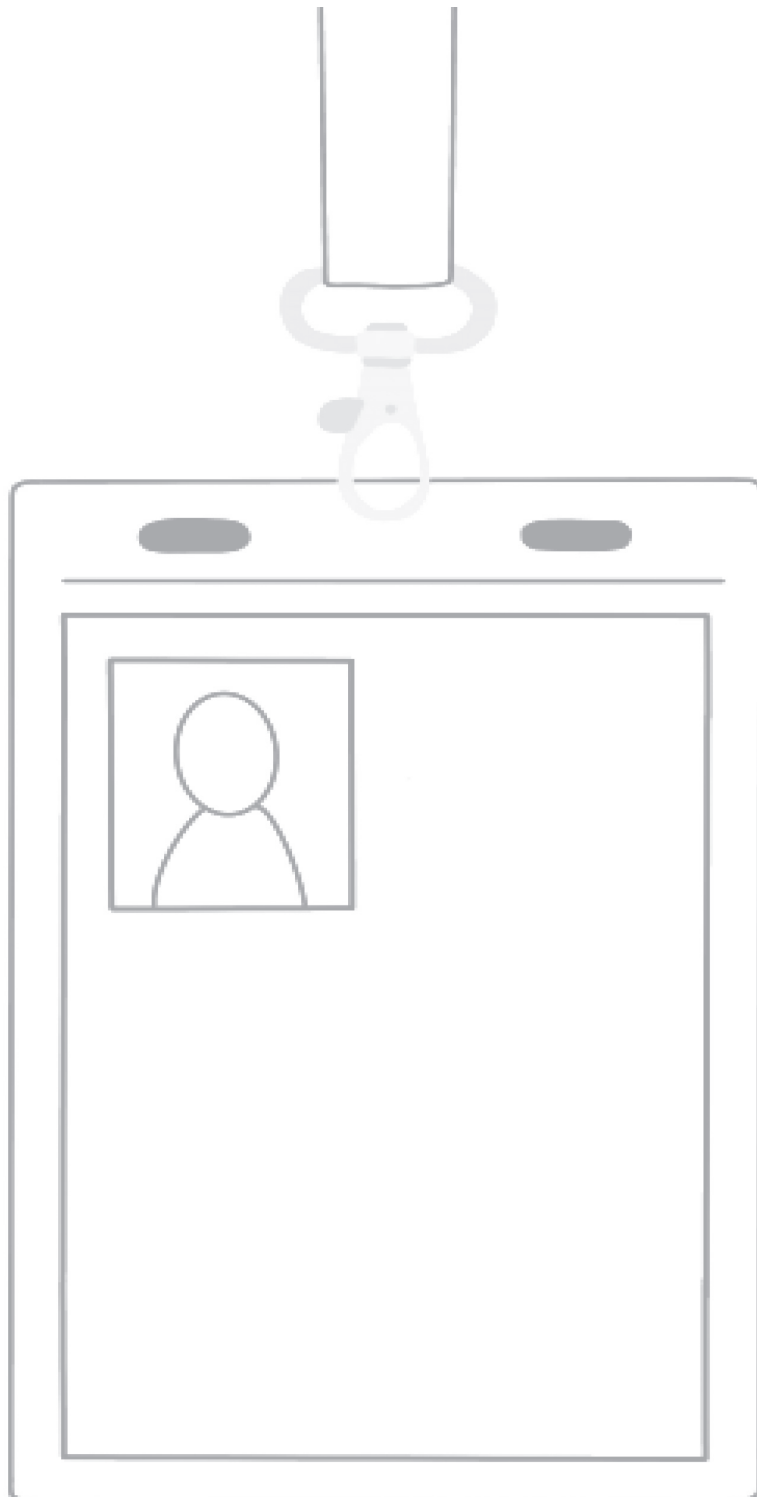
To support discussions about who they are, their interests, hopes and values, group members can design their own shield which represents who they are, their interests, hopes, etc. As with the ID badge activity, they can be guided to think about their values and what is important to them, like honesty, trust, etc. Encourage them to write their own motto on the shield too.

As a group: use a larger copy of the template and complete it as a group, adding the different values, hopes and interests that the group have.



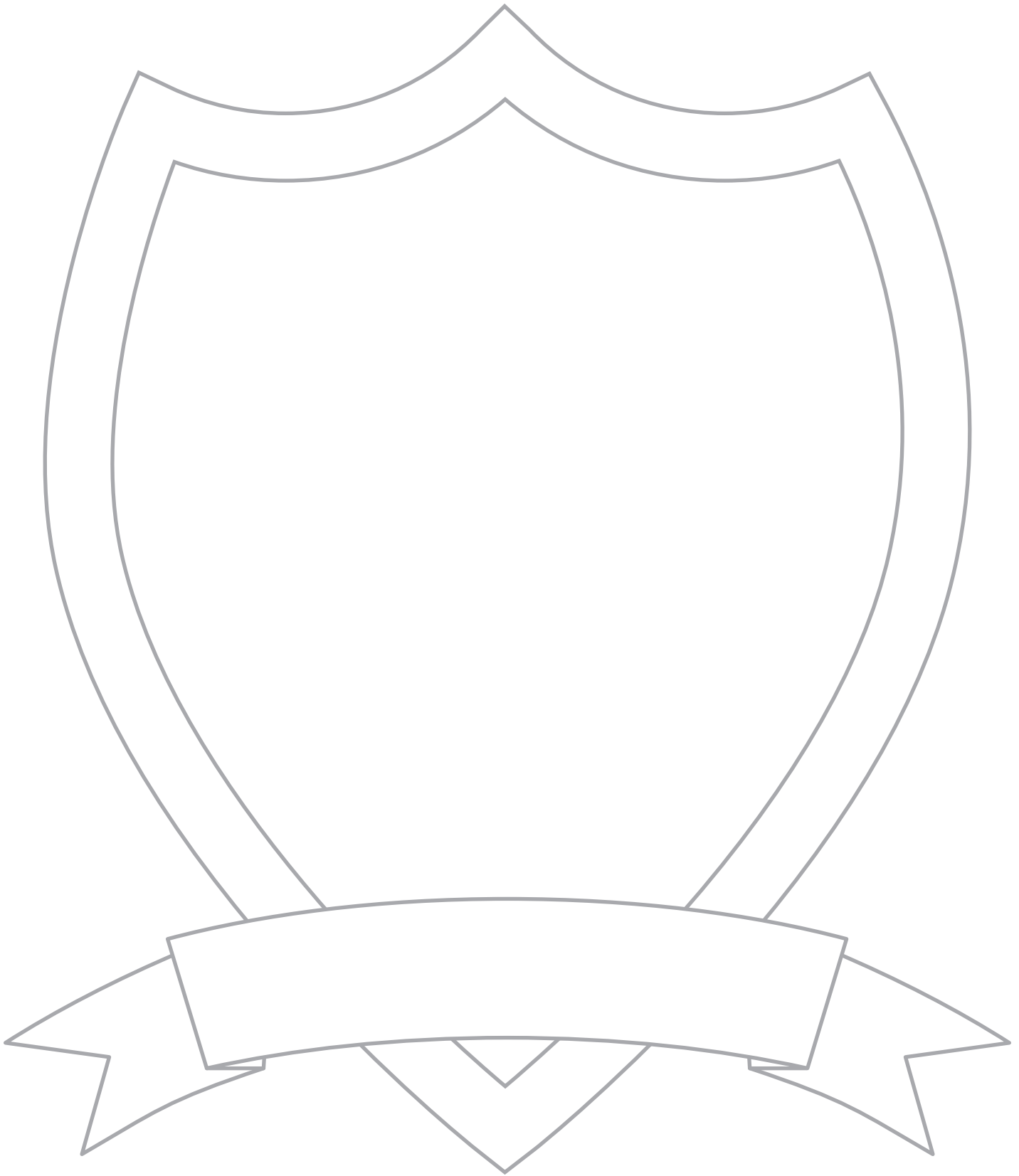


MY ID BADGE





MY SHIELD





EMBRACING MY BODY

Conserving energy, planning and pacing are important strategies for people with long-term conditions to practice but to do them effectively people need to reflect on the impact that different activities have on their energy levels, what triggers their symptoms and how they feel physically and emotionally when they do too much. The activities in this session support people to recognise these feelings, the importance of taking rest periods and develop planning and pacing strategies that help them to conserve their energy.

SUGGESTED ACTIVITY A: Listening to my body

This activity encourages people to become more aware of how their body feels when they experience different symptoms and if any activities/actions make these symptoms worse or better. In the body template each group member writes down their symptoms and next to each one they write or draw how it makes them feel physically and emotionally. This can initiate a discussion in the group about what helps and what makes the symptoms worse and strategies they can use to manage these symptoms, including planning and pacing activities. Some members of the group might have similar experiences and be willing to share the strategies they use.

As a group: use a larger copy of the template or even draw around one of the group members and create a joint symptom map. Ask everyone to contribute a symptom to the template. Then discuss and note on the template possible self-management strategies for each symptom.

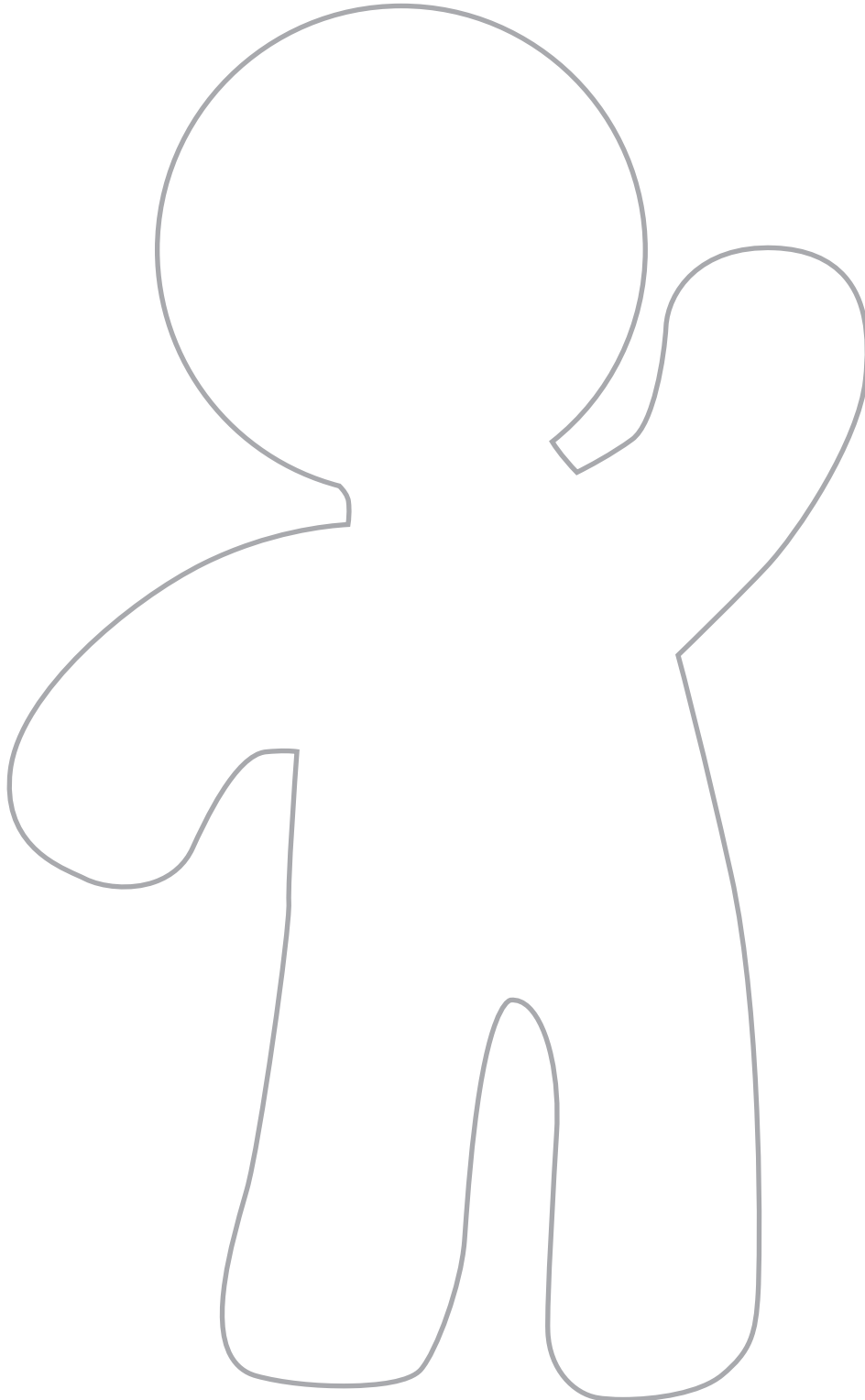
SUGGESTED ACTIVITY B: My pacing journey

This activity supports people to reflect on the impact that different activities can have on their energy levels and how they feel physically and emotionally when they do too much. Using the idea of climbing a mountain, each group member will plan something they want to do or think back to an activity where they pushed themselves too far. They should start by filling their backpack with things they need to prepare for their journey, like a good night's sleep or rest the day before. Also encourage them to think about whether they need a guide on their journey (someone to support them) and who this might be and why. Once they have packed their backpack, they should think about breaking up the activity into different parts and how to build in regular rest periods. At each rest stop they should reflect on how they may feel physically and emotionally and add an image, words, colours or textures to represent these feelings. From this, they can think about ways they can conserve their energy and the importance of taking rest periods.

As a group: use a larger copy of the template and choose an activity that the group agree on. Work through the task as a team and discuss ways to conserve energy and break up the activity and how they might feel physically and emotionally if they do too much.

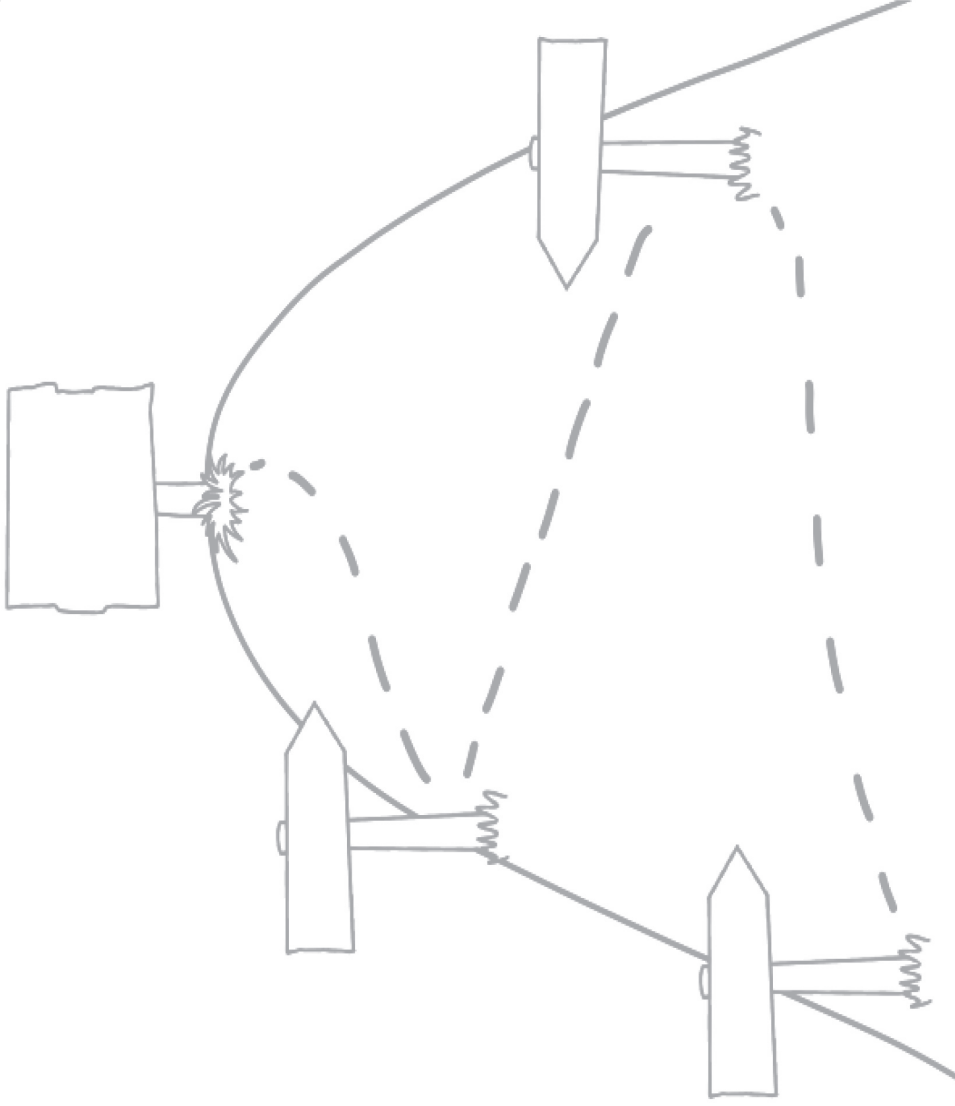
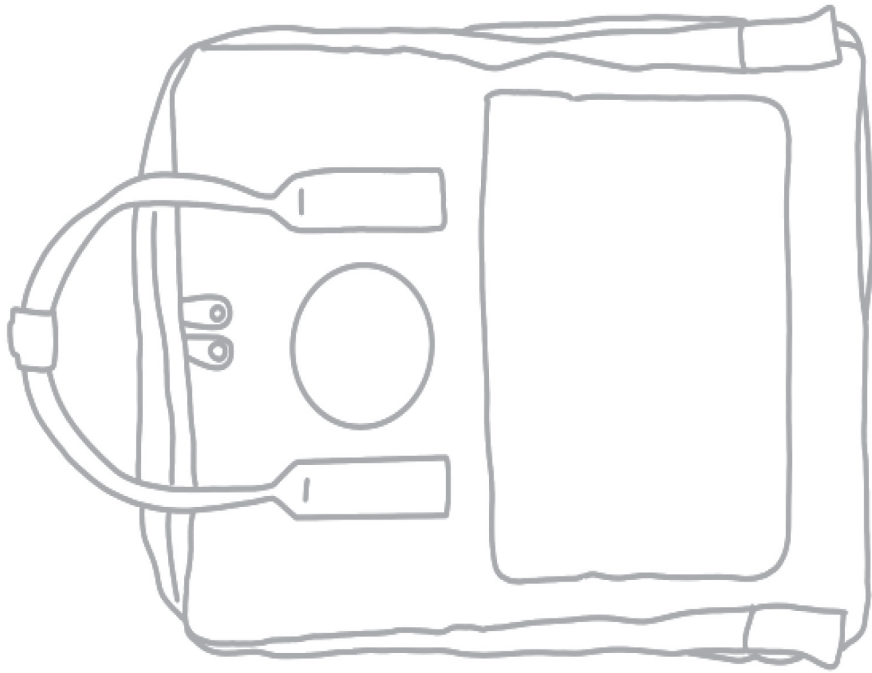


LISTENING TO MY BODY





MY PACING JOURNEY



It can be helpful for people with long-term conditions to learn about how they experience their condition(s) and the impact it has on them in the context on their lives. This session encourages people to be active in learning about their condition and the activities that support them to identify and draw on their strengths, consider how they overcome challenges and ways to set goals for themselves moving forward. This can be difficult for some people, so it can be helpful to encourage them to think about a challenge they have overcome in the past (no matter how large or small) and the strengths and approaches they used to face this challenge.

SUGGESTED ACTIVITY A: My aims

This session considers goal setting but from discussions with people with long-term conditions we chose not to call it this. The session encourages group members to develop some aims that they would like to work towards in the future. It is important to let them determine the time frame which could be a day, a week or a month in the future. The aims can be things like finding time for themselves, learning a new skill or building the confidence to be more assertive. You should work with the group to encourage them to set achievable aims in the time frame they set for themselves and ways to break down the aim into manageable parts. If they use the template provided, they can note their aims in the two spare pieces of the jigsaw and use the pieces in the main jigsaw puzzle to reflect upon and note down things that can help them achieve their aims, like their strengths, information or support they might need and actions they can take. They can use words or images to represent these things.

As a group: use a larger copy of the template and choose an aim that the group agree on. Work through the task as a team and discuss different ways to break down the aim into manageable parts, the things that can help them achieve the aim.

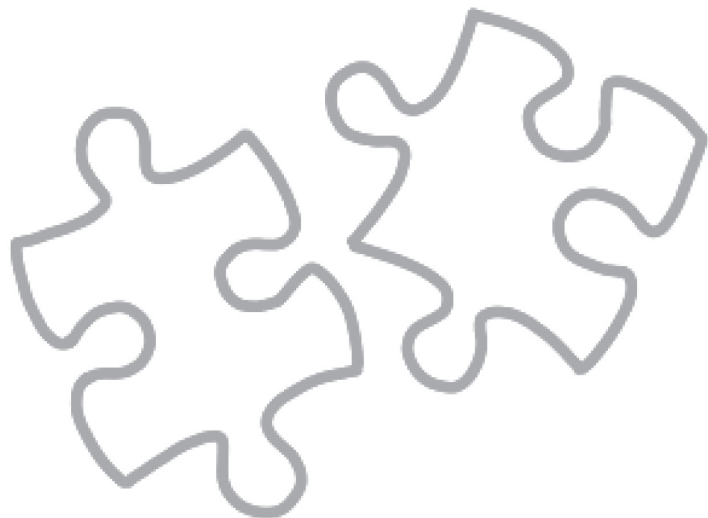
SUGGESTED ACTIVITY B: My strengths tree

When faced with challenges, it can be helpful to encourage people to reflect on their strengths and think about how they can use these to meet these challenges. Creating their own strengths tree can support this. On different parts of the tree people can reflect on different resources: the roots are the experiences from the past that give them stability and/or challenges they have overcome; the branches are the people they can reach out to for support; they can draw their own flowers or fruits on the tree to represent their strengths.

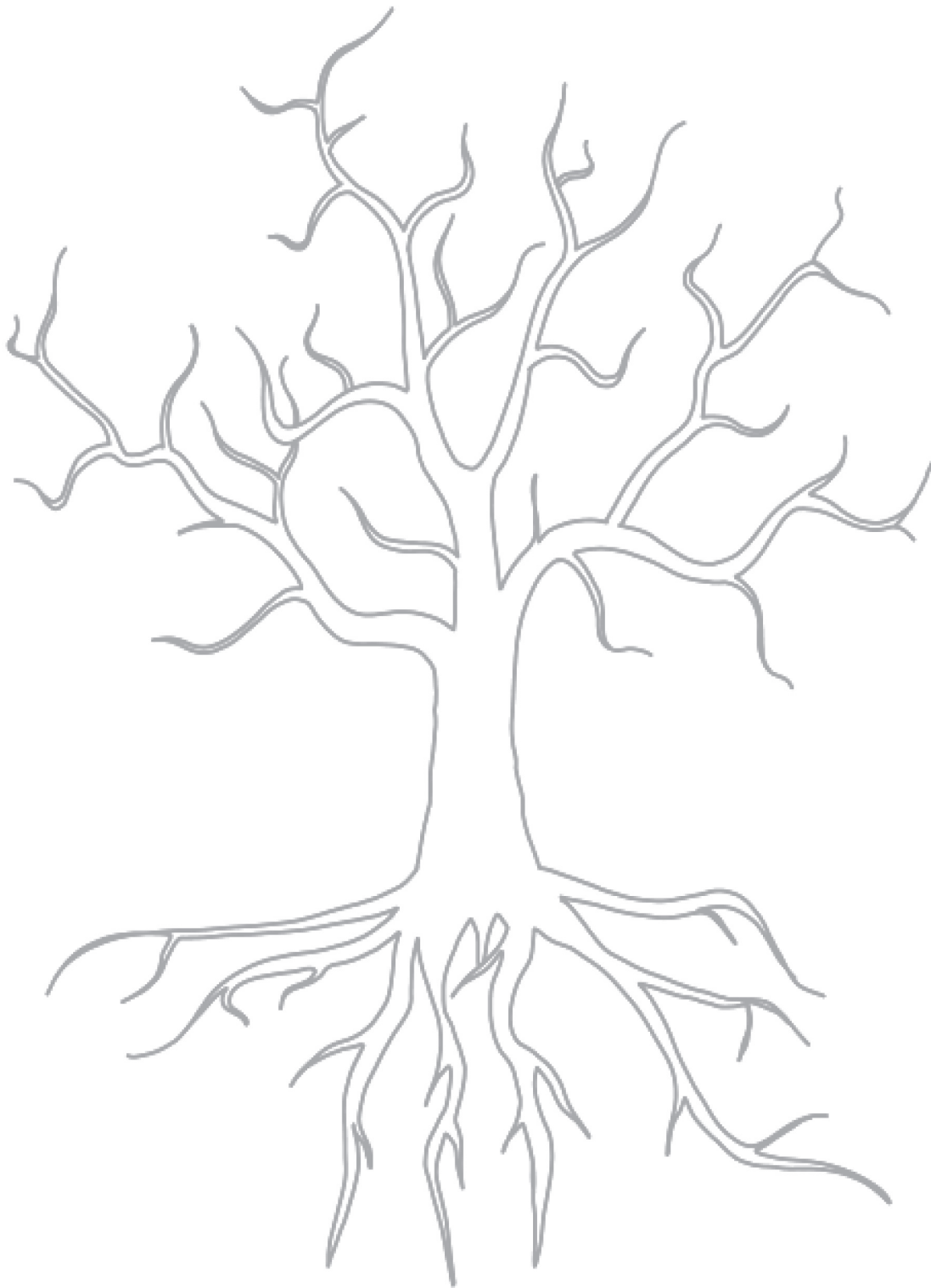
As a group: use a larger copy of the template and create a strengths tree that represents the group. It can be nice to have separate templates of leaves, flowers or fruits that each group member can work on which includes noting their strengths, or perhaps some inspirational words, phrases or images. They can stick these onto the main tree template.



MY AIMS



MY STRENGTHS TREE



CONNECTING WITH OTHERS



In order to explore the social support that people have or need, this session considers the social connections that people have developed or would like to develop and what they value or need from their support networks. It is also important for people to think about how they can communicate their support needs to other people and boost their confidence in communicating their support needs to others. Group members should be encouraged to reflect on their interactions with family and friends, health and social care professionals and other members of the public or organisations.

SUGGESTED ACTIVITY A: My social system

This activity focuses on creating a visual representation of the social networks that people have or would like to have to support them and the things that people need from the support that they receive. It uses the idea of the solar system where group members visualise themselves as the sun at the centre of their social system and consider the planets around them as the qualities they value in the people and networks that can support them (family, friends, groups and even health and social care professionals). Some members of the group might think about the qualities of the support systems they already have in place and can discuss how these support their self-management journey, whilst other might have few support networks and may engage in discussion of where they can find support that meets the qualities that they value. If any group members are particularly creative, they could produce a 3D model of their social system, like a mobile.

As a group: use a larger copy of the template and create a social system that represents the qualities that the group value.

SUGGESTED ACTIVITY B: Message in a bottle

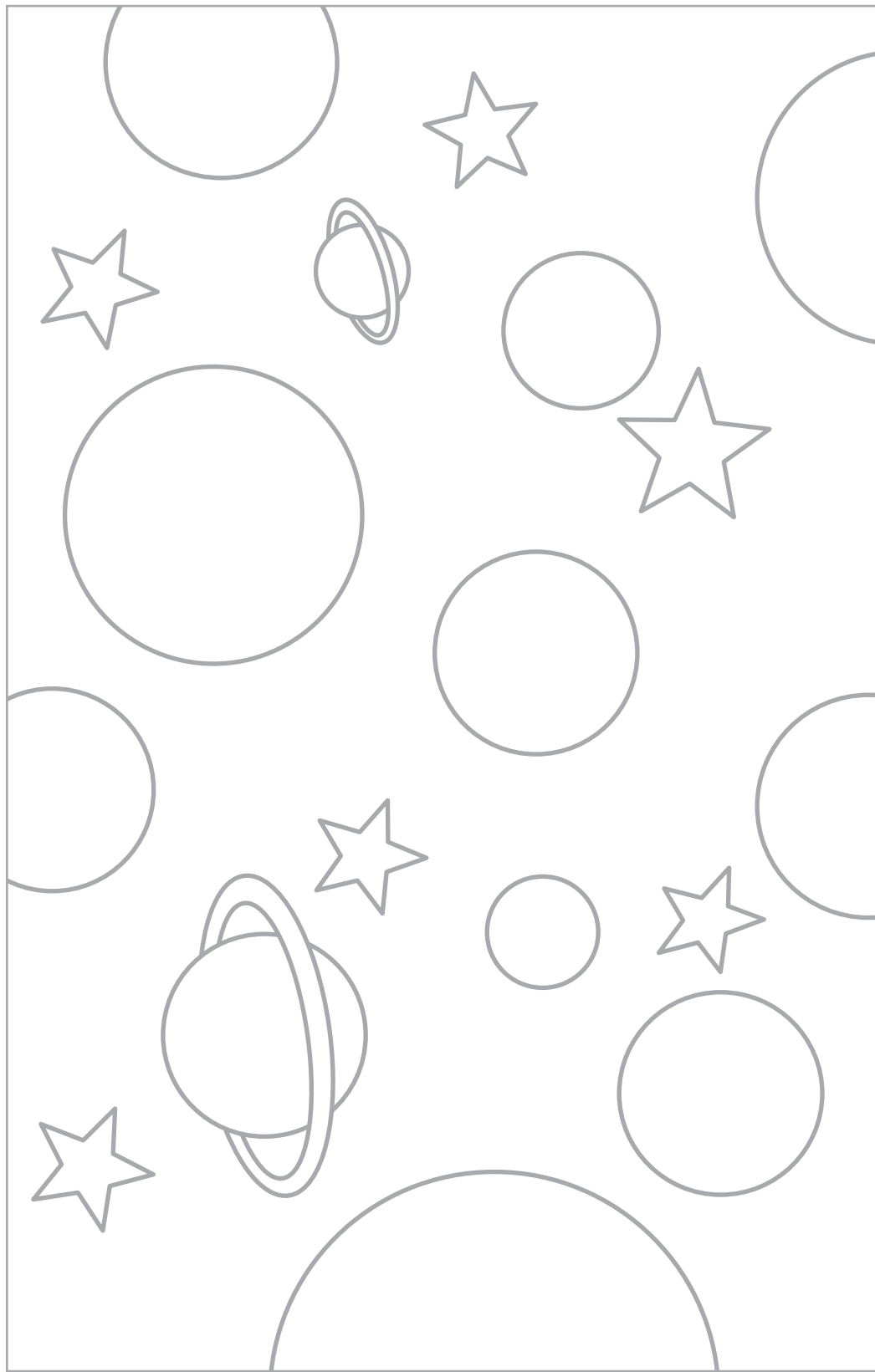
If we do not tell people what support we need from them, they may not know. This activity supports people to reflect on how to communicate their needs to other people, like family and friends, health and social care professionals, members of the public or people from different organisations. Group members will write a message that contains the things that they want other people to know about how their condition(s) affects them and the support that they need from the people around them. Encourage them to think about things people might not know about their condition(s) and to be as direct as possible in their message. Some people might prefer to use particular phrases, poems or song lyrics in their message.

As a group: create a message that tells the world what it is like to live with a long-term condition and what people with long-term conditions need from the people around them and those they come in contact with (e.g. members of the public).





MY SOCIAL SYSTEM



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MESSAGE IN A BOTTLE



What activities give us meaning and purpose in life? Everyone finds purpose in life in different ways. For some it might be about spending time with their family, creating things or having a reason to get out of bed in a morning. They might like to set themselves challenges to work towards or they might want to find more time for themselves. This session gives people space to reflect on what activities are important to them and how to find ways to find time for these activities and for themselves.



SUGGESTED ACTIVITY A: Finding time for me

Prioritising yourself can be difficult, so this activity encourages people to reflect on ways that they can take some time for themselves. Group members can think about life as a game of snakes and ladders, where the 'snakes' are the people or things that get in the way of them finding time for themselves and the ladders are the people or things that help them to find time for themselves. They can be guided to reflect on what activities give them purpose in life and what they could do to get rid of some of the 'snakes' that interfere with doing these activities, as well as how they could make the most of the things that help them to find time for these activities (i.e. the 'ladders').

As a group: you can create a larger version of the snakes and ladders board game where the group members contribute the 'snakes' and the 'ladders' that they experience. By using a larger version they can write their barriers on the snakes and their facilitators on the ladders.

You could even give each member of the group a cut out of a snake and a set of ladders that they write on and even decorate themselves and then stick them on a larger version of the game board.



SUGGESTED ACTIVITY B: Thank you card

Members of the group can reflect on the activities that give them a sense of purpose in life by writing a thank you card for the activities they are grateful for (no matter how large or small).

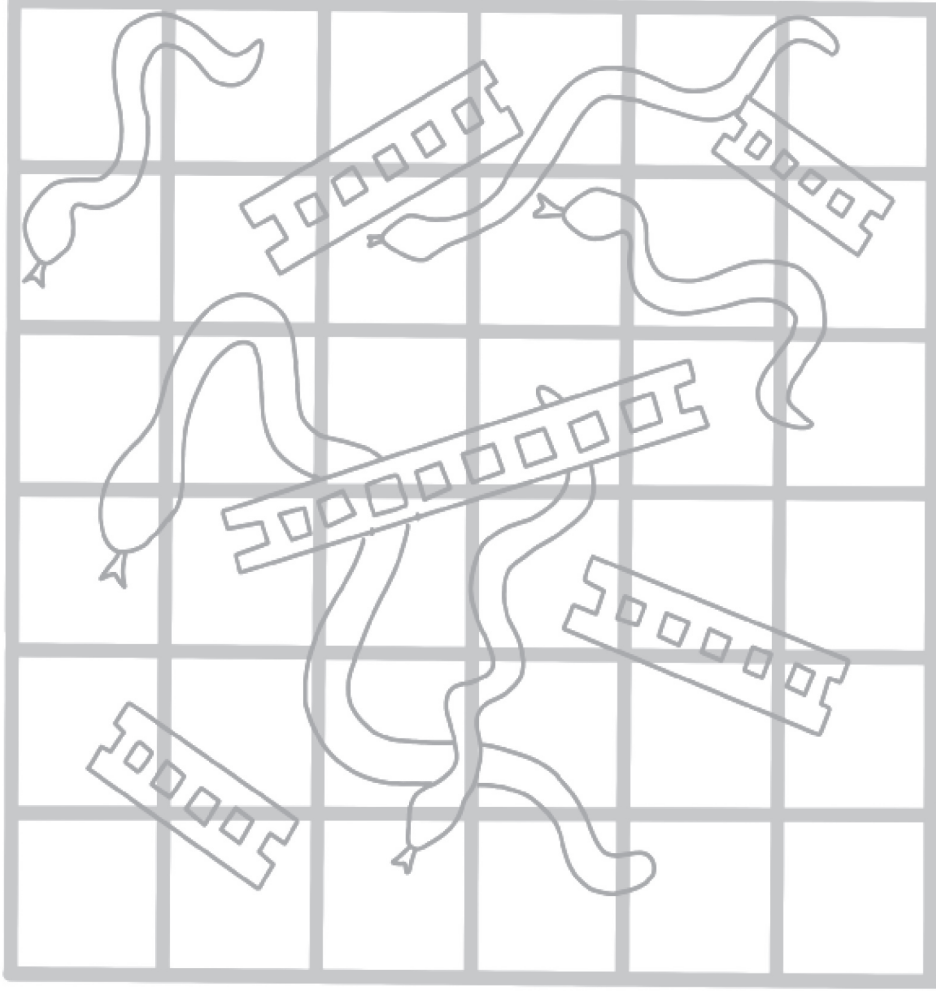
Some people may struggle to identify activities, so discussion within the group about the different activities that are important to them and which give them a sense of purpose in life can help people to identify things that they may find purposeful. They can include images in the card or they may like to write their own verse or poem or just keep it simple with a single sentence. They can decorate the card in any way they like.

As a group: this is a particularly personal activity but the group could create a card as a group that represents what they are grateful for as a group.

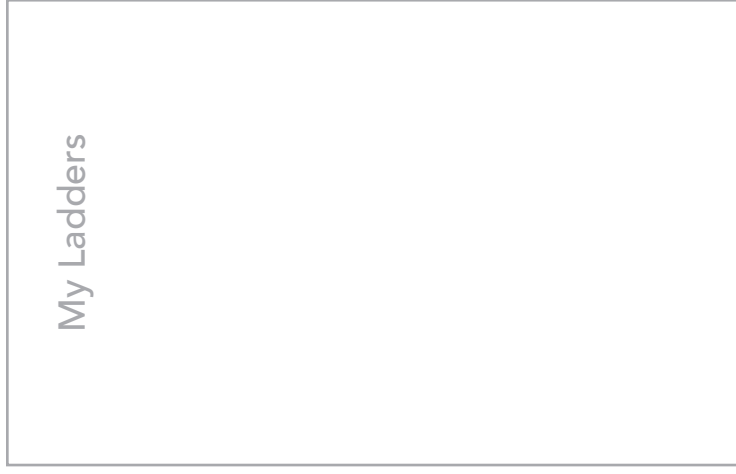


FINDING TIME FOR ME

My Snakes



My Ladders



THANK YOU CARD



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MY JOURNEY

This session can either conclude the programme or be used as a plenary session throughout a rolling or longer-running version of the programme. The aim of this session is to support people to reflect on where they are in their self-management journey and plan their next steps. You might want to refer the group to the My Journey booklet in MyLifeTool to support them to explore their self-management journey so far. It is important that this session is not pitched as a final session because their self-management journey is never-ending. You should explore with the group what they have learnt about their condition and about themselves from taking part in the programme and how they can apply what they have learnt and continue the reflective process moving forward.

SUGGESTED ACTIVITY: **My Vision board**

To support discussions of their self-management journey to date, members of the group will be encouraged to return to the vision board that they created during the first session. They can reflect upon their expectations of the programme and whether these were met, including whether they achieved what they hoped to achieve by taking part in the programme. If they did not achieve what they expected, you can discuss why this is the case; perhaps they expected too much from the programme or from themselves or their condition or life circumstances interfered in their journey. In these cases you may need to explore with them how these interruptions are normal and encourage them not to blame themselves for not reaching a point in their journey that they had hoped to reach. Reiterate that every person's journey is different and even a small amount of progress is positive.

They might want to think about the different elements of self-management and if anything has changed in their views and experiences of how they see themselves, how aware they are of their physical symptoms and pacing themselves, how much they understand their own experience of their condition, how to use their strengths to their advantage, how resilient they are, how their social connections support them in their self-management journey, which activities give them a sense of purpose and how well they manage to find time for themselves. Group members can add to their original vision board or create a new one, using words/phrases, cuttings, images, drawings; anything that represents their journey and where they want to head moving forward.

As a group: if you produced a group vision board in the first session, you can return to that as a group but it is fine if people now want to create their own vision board.





MY VISION BOARD

A template for a vision board. It features a vertical column of four circles on the left side, connected by lines to various rectangular boxes. The top-left box is a large empty rectangle. To its right is a smaller empty rectangle. Below the top-left box is a larger rectangle containing five horizontal lines for writing. At the bottom left is a rectangle with five bullet points on the left side. To its right is a large empty rectangle. At the bottom right is another empty rectangle.



FREQUENTLY ASKED QUESTIONS

Does the programme have to run face to face?

No, the programme can run face to face and online.

Is there a maximum group size?

We recommend no more than ten people per group.

Is there a minimum group size?

We recommend no less than three people per group. This programme is not designed as a one-to-one programme. It uses social interaction to encourage and support reflection on self-management.

What happens if someone misses a session?

People do not have to come to every session. If they miss a session they can still come to the next one.

Can people join the programme halfway through?

We recommend that you run closed groups and do not allow new group members to join after the first session. This helps to create a safe and comfortable space for group members to discuss and reflect upon their self-management experiences.

Can I change the order of the sessions?

Yes, just like MyLifeTool, there is flexibility in how people progress through their self-management journey and you may want to change the order of the sessions to suit the needs of the group. We do recommend, however, that you begin and end with the vision board activity. Session six, "what is important to me" can also be challenging for some people and may be more appropriate to run nearer the end of the programme.

Do you have to include peer mentors when you run the programme?

No, you do not have to include peer mentors.



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ACKNOWLEDGEMENTS

Thank you to our participants for giving their
time to contribute to the development of this
programme.

For support with the design of this handbook,
thank you to:

Small Fry Illustrations

Nick Ball Design



MYLIFE TOOL

Developed by



NEURO KEY

An Alliance supporting people
with neurological conditions



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