

# A guide to setting-up local peer mentor support for people with M.E./CFS



# Introduction

This resource is for anyone considering facilitating peer mentoring for people living with or caring for someone with Myalgic Encephalomyelitis (M.E.), sometimes diagnosed as chronic fatigue syndrome (CFS) or M.E./CFS. Much of this will be applicable to other fluctuating and/or energy-limiting health conditions, including Long Covid.

This booklet shares learning from Action for M.E.'s five-year Mentor M.E. peer support project, setting out how we approached this, and some tools that might be helpful. We don't expect that you will read this booklet as a whole but dip in and out as needed.

Throughout the project, we used a strengths/asset-based approach to peer mentoring. This means that, rather than focusing on barriers and difficulties we focused on what was positive and already present, and could be built on.

Acknowledging that people already have knowledge, skills and talents may help to shift perspective. We can all overlook key resources such as an informal network of support or a possible supporter in our life. Too often, people try to go it on their own. Having a peer mentor can really make a difference to someone's quality of life while living with M.E. or other chronic illness.

## What is M.E.?

M.E. is a long-term (chronic), fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems. M.E. affects an estimated 250,000 people in the UK, and around 17 million people worldwide.

People with M.E. experience debilitating pain, fatigue and a range of other symptoms associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of energy.

Not everyone will experience the same symptoms so it's important not to compare someone who has M.E. to another person who has the illness. People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Some make good progress and may recover, while others can remain ill for a number of years and may not get better. Some people find that they don't go back completely to the way they felt before they became ill, but they do recover sufficiently to lead happy and fulfilling lives. This is similar to many other chronic illnesses.

## Who might use this resource?

If you are someone living with M.E. or any other energy-limiting illness then you might wonder if you could be a peer mentor for anyone else. This can give you a different perspective on your illness and your own abilities and potential. One of our mentors has expressed this better than we can:

*"You may feel that you do not have the skills/knowledge/experience to become a mentor to somebody else, and you may feel you are not equipped to do this or don't have the confidence, but that's ok! Everyone feels like that at the start, but you will soon realise that it's a lot easier than you think. Anyone who is kind, supportive and a good listener can be a mentor, and you could be a big support to someone dealing with M.E. just by creating a space for them to be heard, supported and encouraged. Don't worry too much at the start about the technicalities, you will soon find your way with that, and you will gain confidence as you go. The important thing to think about is that you have something to offer that could make a big difference in someone's life."*

If you believe that you can do this, and your health allows, then it is likely you can. Acting as a peer mentor allows you to feel that you are making a difference, talking with someone and getting a better picture of their life helps you to step outside yourself and see how you might benefit by keeping on doing what you are supporting them to do.

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## Action for M.E.

Action for M.E. takes action to end the ignorance, injustice and neglect experienced by people with M.E. Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure. Further information about Action for M.E. and our work is available at [www.actionforme.org.uk](http://www.actionforme.org.uk)

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## Mentor M.E. peer support network

Mentor M.E. peer support network was a five-year Action for M.E. project funded by the Scottish Government and the Health and Social Care Alliance Scotland (the Alliance) from the Transforming Self Management in Scotland Fund.

Through this project, we worked to develop a network of volunteer peer mentors supporting people living with M.E. in Scotland. We trained and supported peer mentors who offered structured, one-to-one peer mentoring to people with M.E. Later on, we extended this support to people who were caring for people with M.E.

The inspiration for the project came from people with M.E. who, following previous projects, wanted to have access to ongoing support and have opportunities to share experiences constructively. A couple of these people continued to feed into the development of the project and became volunteer peer mentors.

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## Self Management

People living with long-term health conditions that can't be cured can feel more empowered if they have tools and strategies to help them guide and steer their own health alongside health professionals and supporters. It doesn't mean that they are working on their own but that they have the overall picture and inside knowledge on how their body responds and what they see as important in their life. For many people with M.E. this means identifying their priorities, and then pacing themselves and planning.

Knowing yourself and your condition, and getting the help and resources you need from people and organisations in your community to plan, manage and make choices, supports Self Management. Integrating your condition into everyday life and continuing to identify that you are a person with strengths, assets and the ability to make vital contributions can be helpful.

The Alliance's *Guan Yersel* strategy (2008) says that Self Management means:

- being able to find information and resources that might be helpful for your condition and health
- planning and pacing so you can achieve what you find important or meaningful in your life
- being able to get support when you need it.

This might involve managing a range of things such as:

- symptoms – medication, pacing, diet, using aids or equipment, life hygiene (sleep, movement, rest)
- roles – creating/changing and sustaining new meaningful behaviour in life roles (changing responsibilities, redefining, letting go in your family, job or other important roles)
- emotions – acknowledging and expressing emotions that arise from this situation (grief, fear, anger, depression or empowerment, satisfaction, achievement)
- resources – strengths, assets, planning, diary/records, pacing, problem solving, flexibility, sources of support, information and knowledge
- relationships – connection, support, partnerships, networks, friendships.

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## Acknowledgement and thanks

We would like to thank all of the people and organisations that have supported and contributed to the Mentor M.E. project over the years.

The Health and Social Care Alliance Scotland provided the funding for the project through the Transforming Self Management in Scotland Fund. The Alliance was very generous with their time, energy, resources and support. Through attending their networks and meetings, we gained a great deal of knowledge, support and contacts.

The Scottish Mentoring Network was key in sourcing good practice, knowledge and resources that supported developing a peer mentoring project that met high standards. Achieving our Quality Award took hard work but it was worth it to know that we worked in a way that supported high standards in mentoring. Attending the network meeting and events were a key way of staying in contact with progress in mentoring and developments.

We also thank the M.E. Highlands & Islands Network who worked in partnership with us to host many successful Mentor M.E. events.

Thanks to OxygenWorks who were key to our work in the Highlands and were great partners and hosts.

Thanks to all the M.E. support groups in Scotland for welcoming us in and letting us talk about our work.

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## Action for M.E. staff

Thank you for a great deal of insight, support and commitment from Avril McLean, Theresa Burns and Kat Allen who work or have worked for Action for M.E. We are grateful to all the Action for M.E. staff who offered support throughout the development of the project.

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## Mentors and mentees

We would like to thank all the mentors who volunteered for the project and who informed its development through their feedback and support.

Thank you too, to all the mentees who benefited from the project and contributed to its development. We hope it made a difference to your life.

Some of our mentors and mentees wanted to remain anonymous; the following were happy to be named (which we have done in alphabetical order). Without your time, energy, insight and experience, Mentor M.E. and this learning resource would not have been possible. Thank you.

- Rhona Barton
- Carol Berwick
- Stuart Creighton
- Val Davidson
- Charlotte Davys
- Marie-Anne Joannis
- Jan Kerr
- Kelly McLellan
- Hannah Meikle
- Kirstie R Mitchell
- Jo Rowlands
- Douglas Skinner

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# Section one

## What is peer mentoring?

People have different ideas about what mentoring is. It is not:

- resolving someone's difficulties or offering a solution
- giving advice or guidance
- telling someone what to do.

Peer mentoring is about being there to support someone to find their own way and answers. This happens through listening to and observing what they do and say. A mentor commits to building a relationship with a mentee to bring out the best in them, in order to empower them to steer and manage their own lives better.

This requires building a picture of the mentee and what has happened to them up until now. Then you can move on to finding out how they view their world and what their hopes and fears might be for their future. Gaining this knowledge and understanding requires curiosity, kindness and a willingness to listen deeply without expectations. This also allows you to hear what strengths people have developed and how they have overcome difficulties in the past.

## The value of having a peer mentor

Our mentees told us the main value of having a mentor was being able to talk to someone who really understood their M.E. Many people with M.E. never meet anyone else with the illness so being able to seek reassurance and recognition is invaluable.

Being with someone who understands and can offer empathy and support is very powerful. Feeling less alone and misunderstood is often a valued aspect of a peer mentor relationship for people with a chronic health condition.

## What is a peer mentor?

A mentor has a unique role. They provide support in a relationship which is confidential, open, and non-judgmental. They listen and ask questions, which prompt the mentee to reflect on their own development. Mentoring is not about championing the mentee's cause, solving their problems, or telling them what to do.

Mentors providing peer support can offer those they work with a unique opportunity to share experiences and understanding: removing the need to explain M.E. and how it affects your life can feel like a gift to anyone with M.E. Mentors can support mentees to see their life in a different light and to take steps to work towards greater independence and fulfilment.

A good mentor will:

- be warm, friendly, open and honest
- focus on the mentee's goals and how the mentee might achieve these
- be committed to the mentoring partnership and devote the time required
- listen attentively and communicate well
- help the mentee to reflect
- suspend judgement and evaluation
- have empathy
- be their genuine selves
- be able to give constructive feedback and the ability to be a critical friend, if needed
- be able to build and develop positive relationships built on trust
- be able to be encouraging and build confidence
- have integrity
- be able to seek support when needed.

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## What is a mentee?

A mentee is someone who wants to develop their Self Management skills, achieve personal goals or manage their life better while they live with M.E.

Mentees can come to mentoring having identified a specific area of their life they want to work on or develop. They can also use mentoring to spend some time working out what is important to them to focus on in their life.

It is the role of the mentee to:

- identify areas to work on
- work with their mentor to set out goals and aspirations
- think about how they may be able to achieve these goals with support from their mentor
- think about what challenges may be encountered
- be committed to the mentoring partnership and devote the time required.

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## Areas of work for peer mentoring

Some of the areas that people might want to work on might be:

- planning daily tasks so they take less time and energy to complete, eg. laundry, cooking, shopping
- planning and pacing to continue working
- planning and pacing to have a better family life
- creating space to be heard and validated
- creating space for interests or maintaining friendships
- planning a holiday or special event
- getting support to accept the impact of M.E. and be kinder to themselves.

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## Focusing on the mentee

In the mentoring relationship, the focus is always on what the mentee wants to work on, as long as this is realistic. It is not up to the mentor to tell the mentee what to do or where they should focus their energy and time. It may take a bit of time to get to the heart of why they want a mentor and what they hope to get out of the relationship.

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## Accepting and adjusting

A peer mentor can support people to start looking at their illness differently. Accepting that you have M.E. and then adjusting to what that means for you in your life is a key piece of work. It is also very difficult and so to have support to talk about this and then examine what it might look like for you, in your life, is a key task for a mentor and mentee to work on together.

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## Managing energy and priorities

Balancing the demands of life on your energy and health takes a good bit of work. It starts with discovering your baseline – the level of activity you can sustain on a regular basis – then considering pacing – how you balance energy, activity and rest – to manage priorities and plans.

This can be hard for people to do on their own.

Many mentees found that they were better able to manage this balance through working with a peer mentor as it did allow them to see any blips not as failure but a bump on the road.

Action for M.E.'s *Pacing for people with M.E.* booklet (see signposting and useful resources on p 34) offers a detailed guide to managing energy, rest and activity for adults with mild/moderate M.E.

# Section one

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## Setbacks and realistic aims

It may sound discouraging to talk about managing setbacks, but it is realistic. Even a small habit can be difficult to shift, and your ability to accept and adapt can come and go.

When we were learning to walk, we would have fallen over many times but we never stopped or gave up, as it was such an important step. This is the same. Accepting and adjusting to living with M.E. is difficult but the support of a peer mentor does make it easier. It is knowing that you are not alone with this and that other people face similar obstacles and difficulties and share your experiences that makes peer mentoring so valuable.

## Accountability

Some mentees found it useful that they felt accountable to their mentor, giving them focus and taking responsibility for how their Self Management.

## The emotional impact of chronic illness

Some mentees being able to talk openly with their mentor helped them acknowledge the emotional cost of their illness for them. Many people who have to pace carefully must focus on how they live day-to-day and this can leave little energy for dealing with emotions. Others find it draining energy, as they push feelings out of awareness to focus on practical things.

**See resources in Appendices IV and V on p 41–43 on exploring feelings and needs that our mentors have found useful.**

## Tips from our mentors and mentees

### Prioritising your health

Many looked back at how they tried to push on through in the early stages of M.E. and wish that they had done things differently. Re-thinking your job, relationships, roles and responsibilities, sports and interests may be key to getting the space and rest you need to manage your health.

You may be able to come back to or restart some of these areas but you cannot always regain your health. Some felt that they did not understand the importance of their health until it was too late and said it felt very important to highlight the need to focus on your health.

### Pacing and awareness

Pacing yourself to manage your activities and energy levels is the crux of living with M.E. Many people overdo things when they feel a bit better and then have post exertional malaise and may not be able to do what they had planned or needed to do as a result. Knowing your baseline and stopping activities well before you feel the impact is key to keeping a balance.

However, this is very hard as it means that you need to remain aware of how you are when you are doing things. This awareness in itself takes skill, energy and time to learn. Different tools can support this; a diary of activity and rest, for example, can help track the impact of daily tasks.

### Accepting and adjusting

This was a large piece of work for anyone living with M.E. Accepting that you can't do what you used to and the need to limit things is very hard. However, ignoring it and pushing on usually doesn't end well. For many people, slowing down, planning and resting usually meant that they could do more than they had been when trying to push on through. A peer mentor really can help with this.



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## Resting

Stopping and resting enabled many people to do things that they wanted or needed to do. It is a key skill for someone with M.E. to remember to stop, switch off and rest.

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## Problem solving

Looking at situations as a resolvable problem is a good way to break things down and see them in a different light. This can be applied to daily tasks like cooking and laundry and bigger things like planning a social event or a holiday.

Planning systematically and seeing what can be done in small bits or what could be delegated to someone else means that tasks can take up less energy. One of our mentees was able to have their first family holiday in many years, as a result of working with their mentor to consider their options and who could help to adjust things to work for them.

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## Asking for support

Some mentors and mentees hesitated to ask for the help and support they needed in their life. Many feared people would not respond well.

Sometimes this fear was justified, as other people dismissed their illness. People with M.E. often only meet with others when they are at their best, so the impact on their worst days is rarely seen. However, this does not mean that you should never take the risk to ask. Some mentees found it useful helpful to talk their approach through with their mentor, anticipate the barriers that they might meet and have some responses ready. If you don't ask, you will never know if you could be successful.

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## Communication and honesty

Mentees found talking with their mentor helped them feel more confident about how M.E. affects them. Exploring and practising this with a peer mentor enabled some mentees to ask for adjustments at work, talk to important people in their lives, gain space and support for rest, pursue interests and maintain friendships.

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## Research

Our mentors and mentees did a lot of their research when they were diagnosed, as M.E. and its impact is still not widely known or acknowledged in some areas. Family and friends can help with this work.

Many people with M.E. spend a lot of time, energy and money on exploring the different options that might improve symptoms. It is always useful to keep a degree of scepticism when exploring what might work for you. Since the illness can result in varying symptoms and levels of severity then different things work for different people so there will be some trial and error. It can be useful to talk this over with a peer mentor.

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## Maintaining social connections

Although it may be harder to maintain social contacts and networks, mentors and mentees agreed it is very valuable. Isolation is one of the biggest problems that people with M.E. face. It may be that changing the timing, length and medium of communication enables people to stay in contact with their friends and family.

# Section two – How do we do it?

## Challenge and support

To progress, there needs to be a balance between:

- identifying something that is important to the mentee and would make a difference to their life to achieve
- recognition that aiming for something that can't be attained is unhelpful for anyone.

It may take a bit of time to uncover a manageable challenge that would have meaning, then breaking this down into chunks that someone with M.E. or other energy-limiting chronic illness can complete at their own pace.

A mentor can support with rewarding and recognising progress, even though it may look like a very small step to someone without M.E. This can be essential to keep going when things get tough.

A mentor can also support when there is a setback and progress is not possible. This is the very time when encouragement and support is necessary.

## Capacity and energy

Before any discussion of peer mentoring is possible, the mentor has to be clear on what their capacity will be in terms of time, energy and the resources they have to offer. Flexibility is necessary for both parties. People may need to agree how to deal with the need to cancel and re-arrange meetings. It can help to have a structure and clarity about how things will happen so people can feel comfortable.

People need to be mindful of post exertional malaise and that thinking and feeling uses up energy just like physical activity. This means that sessions may need to be short in the beginning so that people don't drain themselves.

We asked Mentor M.E. participants to adhere to a code of practice and it might be useful to use this as a basis for setting up a similar tool that works for you and the person you are peer mentoring.

## Code of practice

### Respect

Dignity and respect will be at the heart of all conduct and agreements between mentors and mentees. Respecting that everyone's experience of living with M.E. is different and accepting how this might affect the mentoring relationship is key to our way of working.

### Equality

Mentors and mentees will work in ways that accept each person for who he or she is, treating him or her well regardless of age, disability, gender identity, race, ethnic or national origin, religion or belief, sexual orientation or socioeconomic background. There will be no direct or indirect discrimination on the grounds of disability, age, gender, sexual orientation, religion or national or ethnic origin.

### Confidentiality

All mentor and mentee personal and sensitive information will be handled confidentially. Any exchange of contact numbers will be part of the agreement between mentor and mentee and this will only happen if both people are happy with this exchange of contact information.

If mentors and mentees meet in other social settings, they will not reveal prior knowledge of each other without previously consenting to this. All of this requires some upfront discussion of what both people are comfortable with in this relationship.

### Boundaries

Mentors and mentees are working together in partnership for an agreed period to support the personal development and Self Management ability of mentees. This is different from a friendship or a dependency relationship.

It is best if mentors don't exchange gifts or money with mentees; or offer meetings or contact outside the mentoring relationship while mentoring someone.

Discussing an agreed ending at the beginning of the mentoring relationship is useful as it allows both people to know that it will end. This helps to provide focus and keep people on track. Once the relationship is heading towards ending, it is up to both people to consider if they want to stay in contact.

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## Honesty

Both people need to be honest about their needs, abilities and how they are affecting one another while they are working together. Any difficulties with conflicts of interest or maintaining agreements should be flagged up as soon as possible so that they can be resolved promptly. Any agreement should anticipate the possibility of mentors and mentees not being a good fit for one another so that a positive ending and/or alternative match can be sought if required.

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## Health and safety

Mentors and mentees will work in ways that ensure their own and other people's safety. Meetings should take place in accessible public spaces that are suitable for both people or online through Zoom, Skype, email or text, keeping in mind confidentiality issues.

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## Different views on M.E.

M.E. is a difficult illness to understand. Research points towards there being different types, or subsets, of M.E. with different causes and symptom patterns. There is new research coming out all the time, but there is still a lot we don't know about the biology of the condition.

It is very important that mentors appreciate the wide range of experiences of symptoms, severity and impacts of living with M.E. Mentors need to be open-minded and to be able to work with and respect differences of view and experience, seeking joint approaches to topics raised by mentees.

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## Setting up and closing down of mentoring

Once you are clear about wanting to provide some peer mentoring, there needs to be a mechanism or process for identifying potential mentors and mentees. People need to be ready for each of the roles with health stable enough to commit to working together, while acknowledging that there may be pauses along the way. The mentor has to be clear that they are able to manage to keep looking after themselves while they mentor someone else.

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## Matching

We used a very simple system of matching people through sharing their approximate locations and possible locations where they might want to meet up. If you are working online then this is not so important.

Then we asked for any key life experiences/interests that they would be keen to have the mentor share or be interested in to work on together. Finally, we asked them to describe themselves in three words. This system seemed to work well.

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## Permission

Just as the mentor gives the mentee permission to be themselves by listening to what has happened and how they are feeling, they also need to give themselves permission to prioritise their needs when their health demands this. It's best to discuss this at the early stages when looking at the ground rules of the relationship.

There also needs to be an understanding that it's OK to end the relationship if it doesn't work for people, and a discussion of the best way to do this.

# Section two

## Limits of the peer mentoring relationship

The mentoring relationship is built on mutual trust and respect, which should shape the boundaries of the relationship. In this context, boundaries means the rules, guidelines, limits and standards that are expected within the relationship, on both sides

The majority of the advice below applies to the mentor, but is useful for the mentee to see too, so they know how the relationship should look and what is expected from both parties.

### Do

- respect each other as individuals
- maintain confidentiality at all times
- let people know as soon as possible if you need to cancel or rearrange a meeting
- keep the focus on the mentees' needs
- operate within the limits of your own competence, referring to others or seeking support when necessary
- be aware of any conflicts of interest and take advice if they are likely to impact on the relationship
- act within the law and don't encourage, assist or collude with others engaged in conduct which is dishonest, unlawful, or discriminatory
- clarify in your agreement with the mentee if you will exchange personal contact details – if this is agreed, any contact must be reasonable and relate only to mentoring.

### Don't

- disclose any personal or sensitive information about the mentee
- accept money or gifts from mentees
- administer medication
- act on behalf of the mentee
- become involved in the mentee's family or other disputes
- force your own views or opinions on another person.

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## Checklist for first meeting with a mentee

It can seem like you need to do many different things at once so it helps if you set aside some time to prepare how you want the session to go and what you want to achieve. It is also useful to think beforehand about how much information about yourself and your circumstance you want to reveal. Thinking this through for yourself helps you to stay within appropriate boundaries in the relationship.

### Create a good rapport

- Introductions
- Your role/ who are you
- Mentee info – name, background info

### State the goal for this session

- Why you are here
- What we hope to do
- What we hope to achieve by the end of the mentoring relationship

### Finding out about the mentee

- Who they are
- Why are they here
- What's been happening
- How they feel about things
- What support is needed

Do this by:

1. Observing
2. Questioning
3. Listening

### Summarise the session

- Clarifying and summarise what has been said
- Action points
- Next steps
- Close conversation

Of course, you may not get through all of these things in the first session or even the first handful of sessions. It may take time to allow the mentee just to speak and to get things out: creating a trusting relationship takes patience and time. You can come back to this structure for later sessions in case things are lapsing into what feels like just a chat although at times, a chat may be all that is necessary.

The amount of time you have to meet up will also limit how much ground you can cover. Both of you need to be honest about your own limits in terms of time and energy available for meeting up. Some people may only want to meet for 30 minutes and some may be able to meet for longer. This limit will guide what you can cover in a session. This may help to give a focus on what is the most useful areas to concentrate on in a session.

# Section three – how does it work?

## Skills and solutions

Peer mentoring involves one person acting as a support to another, helping the mentee to develop skills and solutions in order to make progress in managing their condition or individual circumstances.

Sometimes peer mentors will be drawing on their greater experience in a particular area to help the person they are mentoring find their own solutions. In other cases, peer mentors and mentees will have similar levels of experience, and mentors may find themselves learning alongside their mentees. However, the focus of the mentoring relationship will always be upon supporting mentees to identify their personal goals and/or to work through challenges they have identified.

## Relationship

The mentoring relationship is key to enabling the mentee to progress. This is why it is vital that some groundwork is put in place before people meet up. Being clear about the limits and focus of the relationship helps people to start to be open and trust one another and this improves communication. It may be useful to have a discussion on the ground rules that would work for the both of you at the beginning so that you both feel comfortable.

See Appendix I on p 36 for an example of ground rules you can use.

## Working online

Some mentors and mentees have been happy to work online through, Zoom, Skype or other similar platforms. Meeting online works well for some people with M.E., while others are sensitive to screens or may be impacted in other ways that make working online difficult.

People also used emails, phone calls and texts. It could be the method varies depending on the topic and the fluctuations in health.

Bear in mind the Code of Practice (see p 10) about respecting people's confidentiality and do some thinking about the what and how of sharing and storing personal, sensitive or contact information.

You will need to think ahead about what will happen if the technology goes wrong and the screen freezes or the connection is lost. Should mentors/mentees contact each other via text or wait for the other person to come back in? It can put people at ease to know ahead what will happen when things go wrong.

## Is mentoring a journey or a destination?

Sometimes people come to mentoring with a fixed aim or objectives in mind. Others are not clear what it is that they want. It may take time for the mentee to identify what they want to focus on. Sometimes it may be more a journey that supports the mentee to get to know themselves better so that they can start to manage M.E. and its impact on their life differently. Recognising your strengths and assets and hearing how others have dealt with difficulties can be inspiring.

Too often, people with M.E. lose their jobs, interests and friends. It can be useful to focus on things that will still be a passenger on their journey no matter where it takes them. These passengers might be cherished values, ways of expressing their feelings or how they behave toward themselves and others.

Effective Self Management means that the mentee has uncovered what is important in their life so that they can focus their time and energy on that area. Sometimes, we may have a concrete goal but it may require something from outside or other people to be realised – so we may not always achieve it. However, if we identify how we want to live, and the values and roles that are important to us, then the journey itself will be valuable.

## Endings

Discussing the end of the mentoring relationship at the beginning of mentoring, and referring to it occasionally, means that both people are clear on when this will happen and how it will be managed. If either person wants to end the relationship in advance of this agreed ending, there needs to be a bit of thought about how both people can have the support they need to do this well.

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## Model of mentoring: see, hear, speak

This simple model of mentoring demonstrates that it doesn't need to be complicated to be powerful.

See: Observing, paying attention to the other person, sensing how they may be feeling, being clear about what you intend and the purpose of mentoring

Hear: Listening, giving space, maybe asking, "How did that make you feel?" or "What else was going on?"

Speak: Reflect back what they have said, and what you have seen and felt as a result of them speaking. You might deepen the conversation by asking, 'Tell me more about...'

Keep it open and don't make a judgement or evaluate their experience

One of the most important aspects of a peer mentoring relationship is the opportunity for someone to have their experiences recognised and validated. This is especially true for many people living with M.E. as they may have experienced people (GPs, employers, friends and family) not believing that they are unwell and wanting them to continue as they did before.

This simple "See, hear speak" model is very powerful as many people have a real need to be listened to. This alone can go a good way to someone feeling a bit better about themselves and their health. For many people it may be the first time that anyone has really heard how they feel about living with M.E. Feeling understood and accepted is tremendously powerful.

Although this model is very simple, it is not always easy to offer it. All too often we are listening only to speak, and something someone says may make us think about something in our life and compare their experience to ours. It is good to bring our awareness back to the intention of the mentoring relationship: offering someone support to increase their ability to manage their health and life better.

It is often only when we speak to someone else about something that is bothering us that we begin to understand what is going on for us. A mentor can then start to probe what might be the best way to tackle it or see it in a different light.

# Section three

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## Mentoring process

The mentoring lifecycle moves through five key stages.

### 1. Building rapport

This initial stage of the mentoring relationship is about:

- getting to know one another and assessing whether you are a good mutual fit
- clarifying mentee expectations and agreeing ground rules
- preparing for commitment
- exploring issues identified by the mentee
- agreeing priorities
- developing empathy.

### 2. Setting direction

In this second stage, the mentor supports the mentee to:

- explore what they want to achieve through mentoring
- acknowledge strengths and assets
- clarify their goals
- achieve a greater understanding of the goals, explore challenges and agree priorities
- identify options or alternatives.

### 3. Progression

This is the stage where there should be most progress for the mentee. To facilitate this, the mentor may need to use different skills and tools to support:

- planning actions and prioritising
- building on experience and learning
- acknowledging current development of strengths and assets
- reflecting on current experiences and the mentoring relationship
- monitoring progress
- giving feedback and acting as a critical friend.

### 4. Winding up

This stage occurs when:

- the mentee has achieved their goals
- the mentee is clearer about what they need or want in their lives
- the mentee is clearer on what is important to them
- the agreed plan has been completed
- reflection on progress helps the mentee identify their next steps.

### 5. Moving on

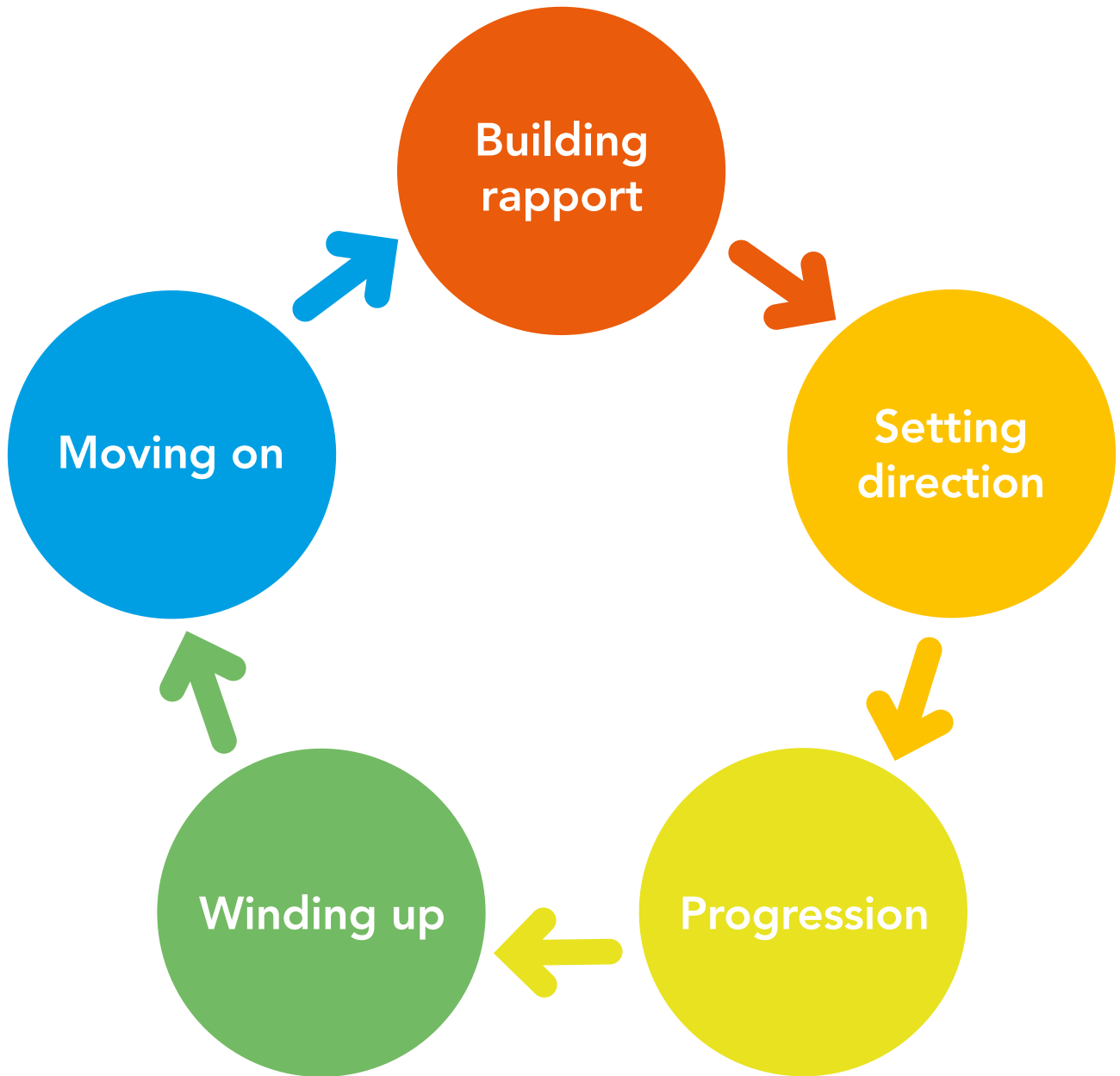
In this stage, there is an opportunity to celebrate success and learning by:

- acknowledging the achievements of the mentee
- reviewing the relationship and its contribution
- addressing feelings and concerns
- sensitively ending the mentoring relationship.

Regular monitoring and review of the progress of the mentoring relationship should help to identify when different stages are complete.

There may be times when stages are repeated for different issues or developments. The full process may need to be repeated and reviewed to check that the goals and plan created are still a good fit for current circumstances.





# Section three

## Mentor/mentee agreement

One of the first tasks the mentor and mentee need to do is to set up their own mentoring agreement. This will outline what they hope to achieve and how they will work together.

Guidance and templates for this are in Appendix II on p 37.

It is useful to keep some notes. It good to think in advance how you will keep this information confidential, and to think about where you will talk to or see your mentee. Even if it is online, other people may pass by your computer and this may be off putting if someone is in the middle of talking about something important.

There is a template for taking notes in Appendix III on p 39.

## Communicating effectively

Good mentoring relationships require good communication. In the beginning, both people need to build rapport and a shared understanding of what they hope to achieve together. Think about how you can support this exchange of information.

Communication is about sending information or messages from one person to another person. Behind this process is:

- the message the person sending information intends to get across
- how the message is transmitted
- how the message is received and interpreted.

There are three types of communication:

- Verbal – listening to people speak and understanding the meaning of what they say
- Written – reading information or messages
- Nonverbal – watching people and imagining how they are feeling and thinking.

We understand and interpret information or messages within the setting we are in, the cultures we belong to and our political, economic and social environments.

With this many factors involved, there is a possibility that the original message can get lost or be misunderstood.

## Verbal communication

Verbal communication is a two-way process. Even for something like a podcast or radio broadcast, the person listening interprets the meaning through his or her own understanding of what has been said. This may depend on how well they have been listening, what else has been on their mind or within their hearing, and how much attention they have paid to what has been going on and what meaning they make of it. This can mean different people having a completely different understanding of the same message.

To communicate effectively:

- use words that can be understood by most people (not jargon or slang)
- ask people to repeat or use different words if you don't understand
- make direct requests and statements when you can
- provide as much information as possible so people can get an understanding of the situation from your point of view
- give information in the right order so people can see where you are coming from
- use appropriate nonverbal communication; your facial and body expressions and tone of voice should match the content of what you are saying.

It may be useful to paraphrase what you think has been said by the mentee. That might mean summarising the main points or using different words to get to the same meaning. This way you can check that you both have the same understanding of what's been said and agreed for the next time.

---

## Written communication

Mentors will need to take some notes during their meetings with mentees as a reminder of what they've covered and agreed, so that they can easily pick up where they left off at the next session.

These notes are for your own use only and you should keep confidentiality in mind.

---

## Nonverbal communication

Nonverbal communication includes people's facial expressions, posture, body language, gestures, and tone and pace of voice. If the person is hesitant to speak, you may be relying on this type of information to judge whether you should probe further on a topic, or leave it alone until they are ready to discuss it.

You are looking to gain information and insight into the mentee's life, but this has to be at a pace that suits them. Allowing silence and space to think about what they want to say may prompt further information. This is especially true if people are suffering from brain fog (problems with memory and mental clarity).

If they don't want to explore an area of their life you should respect this. It may be something they come back to in a later session.

---

## Communication skills

Observing, listening and questioning are key communication skills for any mentor. Using these skills wisely can help to ensure the communication process stays on track and that there is greater understanding between the mentor and mentee.

---

## Observing

The first step in communication is observing what is happening through paying attention to information coming through our five senses. This is the basis of being a good communicator, listening with more than your ears to what is being said – and not said.

In order to prevent us being overwhelmed by sensory information, we use shortcuts such as stereotypes and filter out information, especially if it is at odds with what we know and believe already about something or someone. It's easy for us to miss vital information when we expect things to go along similar lines to our expectations.

Paying attention and shifting our focus means, we can increase our awareness of what's happening and how we feel about it.

---

## Listening

"We have two ears and one mouth so we can listen twice as much as we speak."  
*Epicetus, Greek philosopher, AD55 to AD135*

- Listen to the end – don't finish off people's sentences for them.
- Leave space or be silent – this can allow both people to reflect on what has just been said and it may prompt further information or insight.
- Don't make assumptions – summarising or reflecting back what you think that you've heard may reveal that you have a different understanding.
- Don't listen to respond – stay with what's being said, not your own thoughts about the content.
- Check out your understanding – reframing what has been said and identifying how the mentee feels about it can help build understanding.

# Section three

## Questioning and listening closely

A vital part of the peer mentoring relationship is finding out information. There are different types of questions and each encourages people to reveal different types of information.

## Timed space to speak uninterrupted

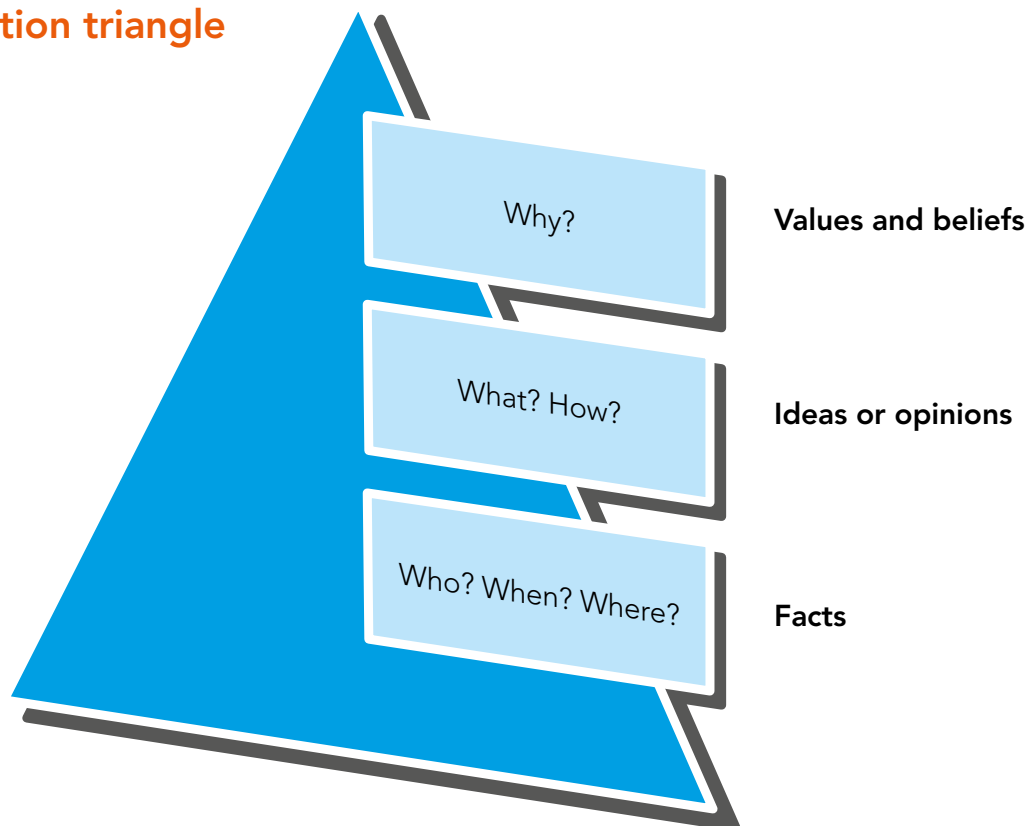
Sometimes it may be useful to set a time, say five or 10 minutes, for the mentee to speak uninterrupted. Knowing that your only role is to listen and observe during this time helps to keep the focus on them. You may then want to do the same for yourself and reflect back what you have heard them say uninterrupted so that you can check your understanding.

## Open questions

Open questions are a useful way of starting a conversation. They open up the discussion, rather than just leading to yes or no answers. Hopefully they will draw out information that could lead to more questions and give you a firm basis for understanding what is happening in this person's life just now.

It may be that the mentee needs some time to think about why they are really in mentoring, open questions can support them to do this thinking. See the open question triangle below for the types of information you can gain through asking why, what, how, who, when or where questions. Questions starting with a "why" should be used carefully as they can make people feel they are being judged, prompting a defensive response

## Open question triangle



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## Probing questions

Probing questions go deeper, once you have some basic information on what is on someone's mind. They may help you clarify what the situation is or exclude things from your enquiry. Examples include:

- Tell me more about...?
- How do you feel about...?
- What makes you think that...?
- Has this happened before? What happened...?
- What else...?

---

## Closed questions

Closed questions are useful for verifying facts. They are called closed questions because they tend to get closed answers like yes or no, or a simple one-word answer.

---

## Rapport

Rapport a close and harmonious relationship in which people or groups understand each other's feelings or ideas and communicate well. In the initial stages of the mentoring relationship, building rapport with the mentee is crucial to its success.

Rapport must be mutual and requires empathy. Some of the tools used to build rapport are:

- being on the person's side, showing understanding of their situation and emotions
- listening to what they are saying and observing their emotions and reactions closely
- mirroring their posture so that they feel you are in harmony with them (this should feel as natural as possible)
- matching tone/tempo – when you speak, use the same tone and pace of voice
- finding common interests and experiences between you.

---

## Empathy

When people show empathy towards us we are on the same level, both being human. Sometimes when people show sympathy instead, because they feel uncomfortable and don't know what to say, it can make us feel small and lesser. Empathy means acknowledging the difficulty and how hard the other person might find it to deal with and accept.

We all have our own unique set of life circumstances and experiences that inform how we see and interpret life. This will be completely different for someone else even if they live with a similar or the same health condition. Recognising, acknowledging and validating someone's experience and viewpoint, even if they are completely different from your own, will make them feel understood.

---

## Nonviolent communication

Nonviolent communication (also referred to as compassionate or collaborative communication) is an approach developed by Marshall Rosenberg in the 1960s. It is based on the assumptions that all human beings have capacity for compassion and empathy, and only resort to unhelpful behaviour when they don't have more effective strategies for meeting needs or dealing with a clash of needs.

It can be useful to keep needs and feelings in mind when listening and reflecting back; and explore what needs are not being met for the mentee just now, causing difficulties.

**There are some lists of needs and feelings in Appendices IV on p 41 and V on p 42 to help prompt this exploration.**

# Section three

## Gathering personal information and stories

If you are working at establishing or maintaining rapport with someone then a large piece of work is collecting and building up personal information and knowledge around them. A structured approach may be useful so that you collect facts rather than your interpretation of what the person said.

The focused conversation method in Appendix VI on p 44 can help you delve down into what is really happening.

Another useful approach to build up a picture of the mentee and their life is FORE, which stands for:

- Family – who is in their family now and their family of origin?
- Occupation – what did they work at or do they work on now?
- Recreation – what are their hobbies or interests?
- Education – what is their educational background, do they enjoy learning?

If you feel it might be useful to get more information or background on the mentee's journey with M.E., the Discovering and sharing your story exercise from Action for M.E.'s *Digital storytelling toolkit* offers questions that can help someone to reflect on the story of their illness.

Find the discovering and sharing your story exercise in Appendix VI on p 45.

## Notes

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## Ending the mentoring relationship

Ending a mentoring relationship may feel difficult or tricky for some people but it's essential that it's planned for and discussed in advance so that it's not a surprise to the mentee when it happens.

The mentoring agreement should have an indication of when the mentoring relationship is planned to end. Of course, this may change over time, as different things are uncovered or encountered. However, it should always be clear that the mentoring relationship will end. It's useful to discuss at the start of the relationship how people would like to mark the end so that there's some thought about how this might be done in a way that's useful for both people.

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## Winding up

If the aims or goals set out in the agreement are nearly achieved then it would be a good idea to raise the issue of ending and when it might happen.

---

## Review and reflection

It would be good practice for the mentor to review and reflect on what's happened and whether the items set out in the agreement have been worked through satisfactorily. If there's still some work to do then creating a plan for completing what needs to be done is a useful way of raising and discussing the end of mentoring.

It's key that the mentee knows what their next steps are going to be and what they need to do. Hopefully, as the result of being mentored, they will feel empowered and readily identify what is the best way forward for them. The mentor may help to signpost onto other resources or organisations that can further support the mentee, if this is needed.

It may be useful to have a final meeting where the activity that was identified at the beginning happens. This may be each person telling the other what they have appreciated about them during the time they have worked together. Capturing any learning would be a good way of keeping the project developing and meeting people's needs.

This may mean looking at what worked well and what was not so useful. This way we can improve and change the way the project operates to better suit people's needs and wishes. This may need both people to be honest about their experiences and how they feel about them. It's important that everyone's contribution is acknowledged and recognised and that any feelings people have because of this experience are dealt with appropriately and sensitively.

---

## Confidentiality

You should continue keeping sensitive and personal information confidential after mentoring has finished.

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## Next steps

After mentoring has finished it may be that people want to keep in touch and be friends. This is up to both people to negotiate and agree. For many people it may be that they want to continue to mentor others or that mentees consider being a mentor themselves.

---

## Unplanned endings

If either person wants to end the relationship in advance of the agreed ending, this needs to be raised sensitively, with consideration of support needed to end the relationship. It's helpful to acknowledge from the beginning that matches may not work so that people do not feel at fault if the relationship doesn't gel.

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# Section four – Mentoring tools, models and resources

A structured mentoring relationship uses tools and models to offer a different focus or framework for thinking about people's life situations or issues, and for managing the mentoring relationship and keeping it on track.

Using a structured approach can help discover behaviour that mentees may want to change, or actions they need to plan so that their experiences or outcomes are more in tune with their values, beliefs and priorities

As we already highlighted some people may not be clear on what they specifically want to achieve, so mentoring may be more about being alongside them in their difficulties rather than focusing on a specific end.

It can be very hard to think clearly when you are unwell but just speaking with someone can make a difference. It can then lead to seeing more clearly what might help you to manage your life. Then planning towards this can start as a key part of mentoring.

---

## GROW model

The GROW model is a tool for action planning, problem solving and goal setting. It is easily understood and straightforward to apply to a large variety of issues and different sets of skills and knowledge can be used at each stage of the process. The mentor can use many questions at any point. The skill is to know which questions to use and how much detail you want to uncover.

The GROW model looks at the mentee's **G**oals, **R**eality, **O**ptions and **W**ay forward (or what Will you do?)

The questions opposite form the basis of a GROW worksheet. They are suggested questions only, as it all depends on what the mentee wants to work on in the session. It may be useful to adapt the questions to suit you and the mentee.

Each mentoring session should work through each part of the GROW process but if you feel that is too much, you can both agree on a reasonable stopping point. You can then pick up at this point in the next session.

See p 27 for more on goal setting and identifying your priorities.



---

## GROW worksheet

### The issue

### Goal – what do you want to achieve

- What do you want to achieve out of the mentoring session/relationship?
- Why are you hoping to achieve this goal?
- What else is important to you in your life?
- What are the expectations of others?
- Who else needs to know about the plan? How will you inform them?
- Is it SMART?
- How will you know you've achieved it?
- What will it look like?

### Current reality – what is happening now?

- What is the reality of the current situation?
- Do you know anyone who has achieved that goal?
- What can you learn from them?
- What can you let go of now?
- Where are you just now?
- What is working?
- What could be better?
- What obstacles do you see?
- What have you done so far?

# Section four

## Options – what could you do?

- What else could you do?
- What if the barriers were removed?
- What factors will you use to weigh up the options?
- What are the pros and cons of this option?
- What could you do as a first step?
- What else could you do?
- Can anyone help you with this?

## Way forward – what will you do?

- ...and when will you do it?
- What might stop you doing this?
- How long will it take?
- Who else should know?
- When will you start?
- Where does this goal fit with your personal priorities now?
- What obstacles do you expect to meet? How will you overcome them?
- How committed are you to this goal?
- What steps do you need to take to achieve this?

## Follow – up review of actions

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## Goal setting

You can only create a useful plan if you have goals that are realistic and meaningful for you. A useful way of approaching goals is to ensure that they are SMART:

**Specific** – if it is too general, how will you plan for or attain it?

**Measurable** – you need a way of knowing you have reached your goal.

**Attainable** – it is disheartening to set a goal that you can't currently attain.

**Realistic** – you can attain the goal given your resources, time available and health.

**Time-bound** – you are able to reach the goal in the time you have within your plan.

It is always useful to keep in mind that when you are living with a fluctuating condition like M.E. it may take longer to do things.

---

## Priority matrix

The tool below, designed by author Stephen Covey, can be used to help your mentee identify which areas of their life or goals are a priority. It can also be useful to identify what is their priority and not what other people think they should be doing, or what they think other people expect them to do to help them to meet their priorities.

This tool also helps someone to look ahead, with hope, as over time many small changes can result in a bigger change that really can make your life better. Focusing ahead can be more useful than looking at what has happened in the past or current difficulties as things can change for the better or stabilize and balance out. The past is not always a reliable guide for our actions. We are not responsible for many things that happen in our life, like becoming unwell, but we can choose to work with ourselves to have the best life we can, given our circumstances and resources. A peer mentor can support someone to look at his or her life with a different perspective or focus.

To have successful long term planning you should focus most of your effort on what is important for you and aim to spend a lot of time working in the quality time area, 2. This way you shouldn't need to rush decisions and your mentee can plan and respond to issues in their life in a considered way.



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# Section four

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## Wheel of life

The wheel of life can give a bird's eye view of a mentee's life, and the chance to see how some of the important areas of their life are balanced with others. This may help if a mentee is unsure of what they need to focus on, and can be a tool to stimulate discussion about what is important for them in their life and where they are having difficulties. Then you can use the priority matrix (see p 27) to see where most of the mentee's time and energy should be directed to have the most return long term.

- Balance is personal and unique to each individual – what may be satisfying or balanced for some may be stressful or boring for others.
- Balance must be assessed over time. A regular check-in (eg. with this exercise) can highlight useful patterns and help your mentees learn even more about themselves. You can do this with them, or recommend they do it for themselves.
- Another option is for your mentee to ask someone who knows them well to complete the scores for them (sometimes it's helpful to see an outside perception of your life 'balance'). Important: This must be someone they trust and whose opinion they value – and remember that others may have hidden agendas.

---

## Detailed instructions

1. Ask your mentee to review the eight categories on their Wheel of life (see p 30 for template and example) and think briefly, what a satisfying life might look like for them in each area.
2. Next, they draw a line across each segment that represents their satisfaction score for each area.
  - Imagine the centre of the wheel is 0 and the outer edge is 10
  - Choose a value between 1 (very dissatisfied) and 10 (fully satisfied)
  - Now draw a line and write the score alongside (see example above)

**IMPORTANT:** Ask them to use the **FIRST** number (score) that pops into their head, not the number they think it should be!

The categories should together create a view of a balanced life for them. If necessary, they can split category segments to add in something that is missing, or re-label an area to make it more meaningful for them. For example:

- Family and Friends: Split into separate categories
- Significant Other: Changing the category name to Dating, Relationship or Life Partner
- Career: Changing the category name to Motherhood, Work, Business or Volunteering
- Finances: Changing the category name to Money, Financial Security or Financial Wellbeing
- Health: The category name could be split or changed to Emotional, Physical, Spiritual or Wellbeing.
- Home Environment: The category could split to include Work Environment if needed.
- Fun & Leisure: The category name could change to Recreation
- Personal Growth: The category name could change to Learning, Self-Development or Spiritual
- Other categories to add could include Security, Service, Leadership, Achievement or Community

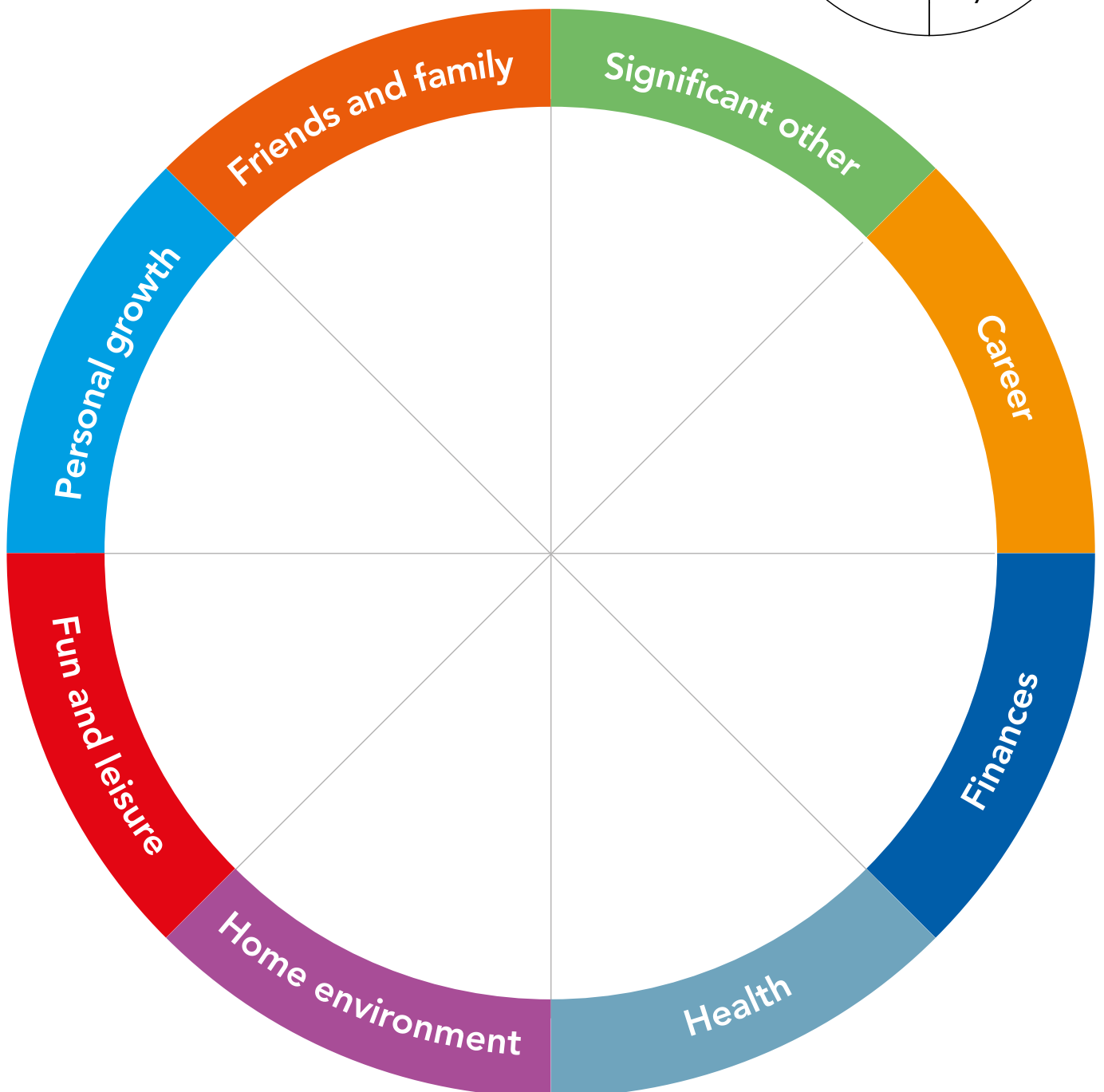
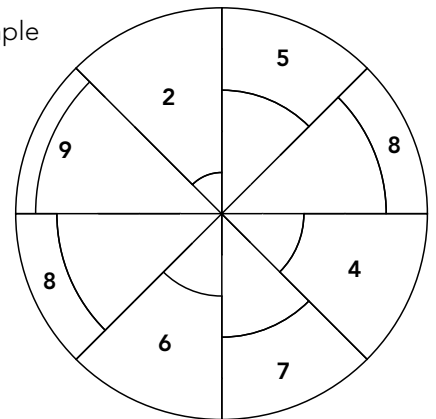
- 
3. Now ask them to rank their level of satisfaction with each area of their life by drawing a line across each segment. Ask them to place a value between 1 (very dissatisfied) and 10 (fully satisfied) against each area to show how satisfied they are currently with each category in their life.
  4. The new perimeter of the circle represents their Wheel of life. You can ask your mentee, "Is it a bumpy ride?"
  5. Now, looking at the wheel here are some questions to ask your mentee to take the exercise deeper:
    - Are there any surprises for you?
    - How do you feel about your life as you look at your Wheel?
    - How do you currently spend time in these areas? How would you like to spend time in these areas?
    - What would make that a score of 10?
    - What would a score of 10 look like?
    - Which of these categories would you most like to improve?
    - How could you make space for these changes in your life?
    - What help and support might you need from others to make changes and be more satisfied with your life?
    - What change should you make first? And what change do you want to make first?
    - If there were one key action you could take that would begin to bring everything into balance, what would it be?
  5. Taking action – the final step. To wrap-up, the exercise you can ask your mentee to identify one action for each area, and then pick up to three actions to get started. You could also ask them to choose the three areas they most want to work on and identify an action for each. TIP: If your mentee is extremely busy or stressed try asking, "What is the smallest step you could take to get started?"

# Section four

Your name: \_\_\_\_\_

Today's date: \_\_\_\_\_

Example



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## Rule of three

It can be useful to keep in mind the “rule of three” when starting to plan activities or areas to work on with a mentee. You can see this rule in speeches and writing, as grouping things in threes seems to make their impact more powerful.

This means identifying three areas of life to concentrate on, or three actions. Of course, this could be done in stages, with one area/action being identified as the most useful place to put attention and energy. It can be good to rule things out for the moment so that it sets limits and things don't seem overwhelming.

---

## Resistance

Once you start to get further into mentoring then you may encounter a time when things just don't seem to be progressing and it's not clear why.

Very often this may be the progress that is most needed and will make the most productive change in the mentee's ability to manage themselves and their life, yet it doesn't happen. If you have built up trust and feel that they might be open to talking about this, ask some questions and listen deeply to the responses. It might be that it feels like too much of a risk to make this change or they feel anxious in case it doesn't work. Just giving your mentee the space to talk, be listened to and to hear themselves may help them to see things differently.

Of course, at times, things will need to be paused because people need to rest or something else is impacting on their life. This is to be expected. The focus is always on the needs of the mentee. If the mentor also has M.E then they must be able to pause when they need it for themselves.

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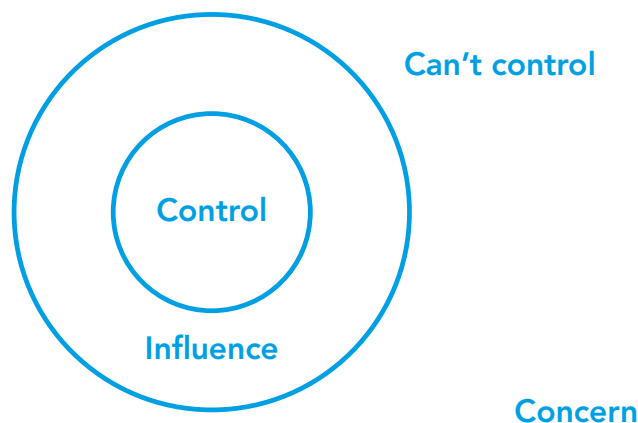
## Circle of influence

This is Stephen Covey's model of the circle of influence. It may be useful to keep this model in mind while talking with a mentee.

We only have a small area of life that we can directly control: this is the circle in the middle. This is the area where the mentee should be working most as they will be able to make most impact. It can help to use this with the priority matrix (see p 27) to identify these areas.

Out at the next level, their circle of influence, they may or may not be able to change things. This may include getting their employer to understand how M.E. affects them and what adjustments they might need to work better; getting their partner, family or friends to understand why they can't always commit to meet up or might cancel arrangements, and to accept and respect this aspect of them.

The circle of concern is the wider world and all that happens in it. We can't control the weather, the economy or actions of many other people and organisations in the world. Although things can be changed over time especially when people band together to take action, it can be helpful to separate out what you can directly control and influence so that you focus on these areas as your actions will have more impact.



# Section four

## Mind map

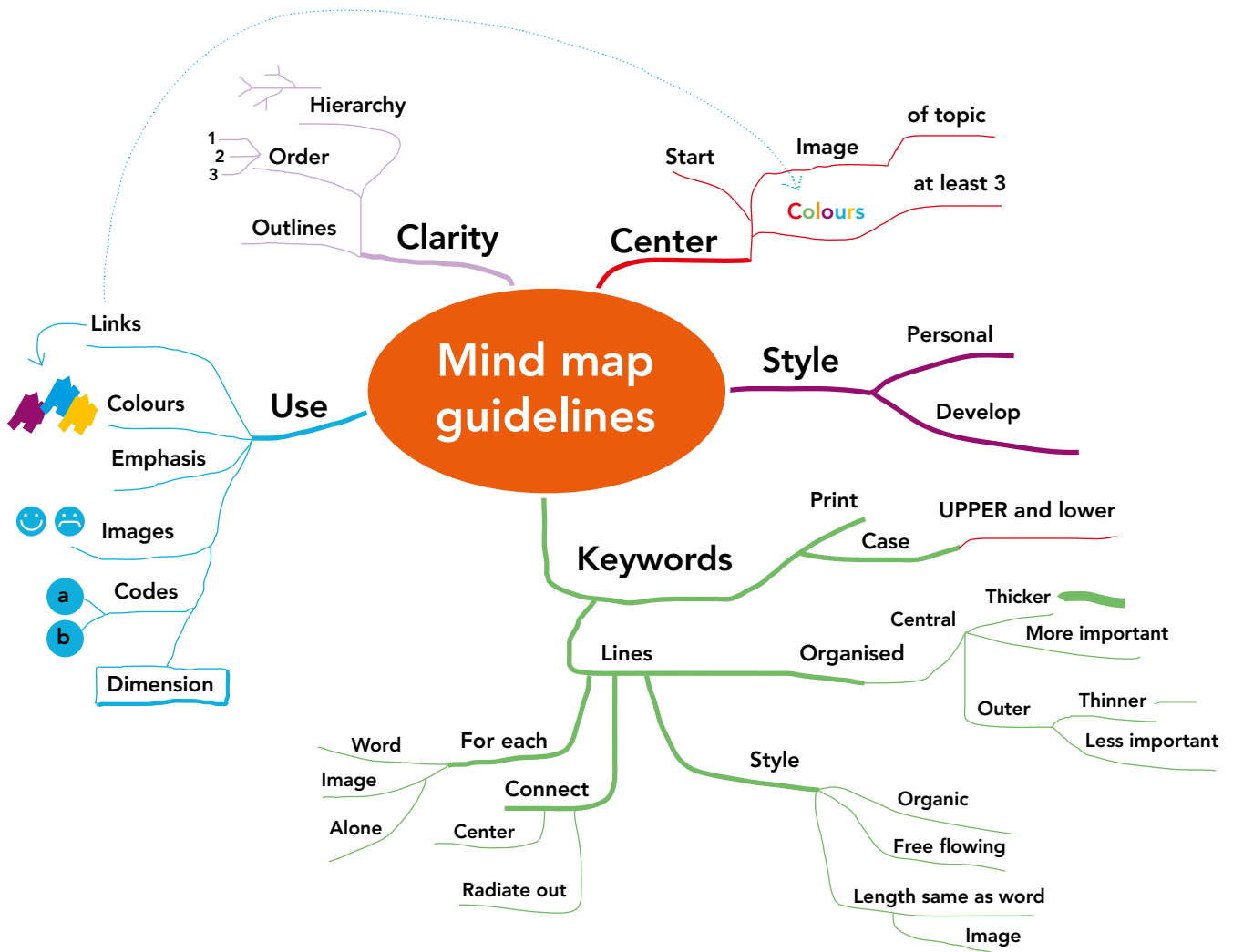
A mind map is a good way to gather information, and look at problems or how someone wants to develop something but is not sure what else is involved.

Put the central theme, problem or idea in the centre of a blank page and then note down any relevant ideas that lead on from this. You can use words or images.

This allows you to see all the different areas and how they might be related. You can see connections and allow ideas to develop out of this. This can be helpful as a planning tool as it shows the different layers of planning that may be needed to get to an end point in the future. It may help people with brain fog to start planning, returning to this when they can and picking up at a point that appeals now rather than feeling it is a linear process that has been interrupted.

## Decision tree

A decision tree can support people to visually represent the situation they face and the possible outcomes of decisions they may make. They can then map out the options and choices they face and what each choice may lead to in the future. This is likely to be more options, choices and decisions and so it can be useful to see that this can lead to potentially very different outcomes.





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## Notes

# Section five – Signposting

## Living with M.E.

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Email: [questions@actionforme.org.uk](mailto:questions@actionforme.org.uk)  
[www.actionforme.org.uk](http://www.actionforme.org.uk)

*Pacing for people with M.E.* by Action for M.E.  
[www.actionforme.org.uk/pacing](http://www.actionforme.org.uk/pacing)

*Taming the gorilla: a guide to living and learning with M.E.* by Action for M.E.  
[www.actionforme.org.uk/taming-the-gorilla](http://www.actionforme.org.uk/taming-the-gorilla)

*This is M.E. and Nothing about M.E. without me, self-advocacy resources* by Action for M.E.  
[www.actionforme.org.uk/advocacy](http://www.actionforme.org.uk/advocacy)

*Severe M.E.: a guide to living* by Emily Collingridge  
[www.severeme.info](http://www.severeme.info)

*Pacing*, a short film by Dialogues for ME/CFS  
[www.dialogues-mecfs.co.uk/films/pacing/](http://www.dialogues-mecfs.co.uk/films/pacing/)

*This is M.E.* film by Josh Pickup exploring “Spoon Theory” told through the eyes of a young woman with M.E.  
[www.vimeo.com/338532785](http://www.vimeo.com/338532785)

Self-management navigator tool by Pain Concern  
[www.painconcern.org.uk/the-navigator-tool/](http://www.painconcern.org.uk/the-navigator-tool/)

*Pharmacy and M.E.* by Action for M.E.  
[www.actionforme.org.uk/pharmacy](http://www.actionforme.org.uk/pharmacy)

## Work, welfare benefits and finances

M.E. and work, including guide for employers, by Action for M.E.  
[www.actionforme.org.uk/employment-support](http://www.actionforme.org.uk/employment-support)

Access to Work  
[www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)

Advisory, Conciliation and Arbitration Service (ACAS)  
Helpline: 0300 123 1100  
[www.acas.org.uk](http://www.acas.org.uk)

Citizen Advice Scotland (CAS)  
Helpline: 0800 028 1456  
[www.cas.org.uk](http://www.cas.org.uk)

Disability Law Service (DLS)  
Helpline: 0207 791 9800  
Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)  
[www.dls.org.uk](http://www.dls.org.uk)

Equality Advisory Support Service (EASS)  
Helpline: 0808 800 0082  
[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

Money Advice Service  
Helpline: 0800 138 7777  
[www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)

Pensions Advisory Service  
Helpline: 0800 011 3797  
[www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)

## Caring

*Caring for someone with M.E.* by Action for M.E.  
[www.actionforme.org.uk/carers](http://www.actionforme.org.uk/carers)

Carers Centres  
[www.mygov.scot/carers-centres](http://www.mygov.scot/carers-centres)

Carers UK  
Helpline: 0808 808 7777  
Email: [advice@carersuk.org](mailto:advice@carersuk.org)  
[www.carersuk.org](http://www.carersuk.org)

Care Information Scotland  
Helpline: 0800 011 3200  
[www.careinfoscotland.scot](http://www.careinfoscotland.scot)

## Emotional support

Samaritans  
Helpline: 116 123  
Email: [jo@samaritans.org](mailto:jo@samaritans.org)  
[www.samaritans.org/samaritans-in-scotland](http://www.samaritans.org/samaritans-in-scotland)

Breathing Space  
Helpline: 0800 83 85 87  
[www.breathingspace.scot](http://www.breathingspace.scot)

Scottish Association for Mental Health (SAMH)  
Helpline: 0344 800 0550  
Email: [info@samh.org.uk](mailto:info@samh.org.uk)  
[www.samh.org.uk](http://www.samh.org.uk)

United to Prevent Suicide  
[www.unitedtopreventsuicide.org.uk](http://www.unitedtopreventsuicide.org.uk)

Support in Mind Scotland  
[www.supportinmindscotland.org.uk](http://www.supportinmindscotland.org.uk)

Penumbra  
[www.penumbra.org.uk](http://www.penumbra.org.uk)

The Spark  
Relationship Helpline: 0808 802 2088  
[www.thespark.org.uk](http://www.thespark.org.uk)

## NHS

NHS 24  
Helpline: 111  
[www.nhs24.scot](http://www.nhs24.scot)

NHS Inform  
[www.nhsinform.scot](http://www.nhsinform.scot)

Patient Advice and Support Service  
Helpline: 0800 917 2127  
[www.cas.org.uk/pass](http://www.cas.org.uk/pass)

## Older people

Age Scotland  
Helpline: 0800 12 44 222  
[www.ageuk.org.uk/scotland](http://www.ageuk.org.uk/scotland)

Silverline  
Helpline: 0800 4 70 80 90  
[www.thesilverline.org.uk](http://www.thesilverline.org.uk)

Royal Voluntary Service  
Helpline: 0808 196 3646  
[www.royalvoluntaryservice.org.uk](http://www.royalvoluntaryservice.org.uk)

Care and Repair Scotland  
[www.careandrepairsotland.co.uk](http://www.careandrepairsotland.co.uk)

## Families and young people

Childline  
Helpline: 0800 1111  
[www.childline.org.uk](http://www.childline.org.uk)

Young Scot  
[www.young.scot](http://www.young.scot)

Parent Club  
[www.parentclub.scot](http://www.parentclub.scot)

Mind yer Time  
[www.mindyertime.scot](http://www.mindyertime.scot)

## Other advice and information

A Local Information System for Scotland  
[www.aliss.org](http://www.aliss.org)

Healthy Working Lives  
Helpline: 0800 019 2211  
[www.healthyworkinglives.scot](http://www.healthyworkinglives.scot)

AbilityNet  
Helpline: 0800 048 7642  
Email: [enquiries@abilitynet.org.uk](mailto:enquiries@abilitynet.org.uk)  
[www.abilitynet.org.uk](http://www.abilitynet.org.uk)

Ask Sara  
[asksara.livingmadeeasy.org.uk](http://asksara.livingmadeeasy.org.uk)

Citizen Advice Scotland (CAS)  
Helpline: 0800 028 1456  
[www.cas.org.uk](http://www.cas.org.uk)

Disability Information Scotland  
Helpline: 0300 323 9961  
Email: [info@disabilityscot.org.uk](mailto:info@disabilityscot.org.uk) Top of Form  
[www.disabilityscot.org.uk](http://www.disabilityscot.org.uk)

Disability Rights UK  
[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

Disabled Motoring UK  
Helpline: 01508 489 449  
Email: [info@disabledmotoring.org](mailto:info@disabledmotoring.org)  
[www.disabledmotoring.org](http://www.disabledmotoring.org)

Motability  
Tel: 0300 456 4566  
[www.motability.co.uk](http://www.motability.co.uk)

Disabled Living Foundation  
Helpline: 0161 214 4590  
Email: [info@disabledliving.co.uk](mailto:info@disabledliving.co.uk)  
[www.disabledliving.co.uk](http://www.disabledliving.co.uk)

LGBT Health  
Helpline: 0300 123 2523  
[www.lgbthealth.org.uk](http://www.lgbthealth.org.uk)

Rape Crisis Scotland  
Helpline: 08088 01 03 02  
Email: [support@rapecrisisscotland.org.uk](mailto:support@rapecrisisscotland.org.uk)  
[www.rapecrisisscotland.org.uk](http://www.rapecrisisscotland.org.uk)

Scotland's Domestic Abuse and Forced Marriage Helpline:  
Helpline: 0800 027 1234  
Email: [Helpline:@sdafmh.org.uk](mailto:Helpline:@sdafmh.org.uk)  
[www.sdafmh.org.uk](http://www.sdafmh.org.uk)

Scottish Legal Aid Board  
[www.slab.org.uk/new-to-legal-aid/find-a-solicitor](http://www.slab.org.uk/new-to-legal-aid/find-a-solicitor)

Shelter Scotland  
Helpline: 0808 800 4444  
[www.scotland.shelter.org.uk](http://www.scotland.shelter.org.uk)

Self-Directed Support Scotland (SDSS)  
[www.sdsscotland.org.uk](http://www.sdsscotland.org.uk)  
[www.in-controlscotland.org](http://www.in-controlscotland.org)

Turn2us  
Benefits calculator and financial support advice  
[www.turn2us.org.uk](http://www.turn2us.org.uk)

# Appendices – Forms and templates

## Appendix I: Ground rules

It's essential for the development of mentoring that both people agree on the ground rules of how the mentoring relationship will be managed. These can be included in the mentoring agreement (Appendix II) if necessary. Before you get into the heart of what you hope to achieve it's useful to look at, discuss and decide on how you will work together. This section offers questions that will help explore this.

## Expectations

1. Are we clear about our expectations of:
  - a) each other?
  - b) the mentoring relationship?
  - c) what we hope to achieve or learn from each other?
2. How closely do our expectations match?
3. How directive or non-directive should the mentor be in each meeting?
4. What are the core issues or areas we want to discuss? Health, relationships or goals?
5. What are the limits to the discussion (what will we/won't we talk about?)
6. Who will take responsibility i.e. the mentor/mentee/both together for:
  - a) deciding how often we meet?
  - b) setting the agenda for meetings?
  - c) ensuring that meetings take place?
  - d) organising where to meet, and for how long?
  - e) initiating reviews of progress?
7. How formal or informal do we want our meetings to be?
8. Are we agreed that openness and trust are essential? How will we ensure that they happen?
9. Are we both willing to give honest and timely feedback (e.g. to be a critical friend?)
10. Do we both agree to behave in a confidential and ethical manner?
  - a) How will we ensure that we do this?
  - b) What will we do/not do?
11. What are the limits to the confidentiality of this relationship?
12. What are we prepared to tell others about
  - a) the relationship?
  - b) our discussions?
13. Who shall we tell and how?
14. What responsibilities do we owe to others because of this relationship?
15. When and how will we check that this relationship is 'right' for both of us?

---

## Appendix II: Mentoring agreement

We are voluntarily entering into a mutually beneficial relationship. It is intended this relationship will be a rewarding experience and that our time together will be spent in personal development activities.

**Start date**

**Duration of mentoring** (3,6 or 9 months)

---

**Frequency of meetings** (Fortnightly/monthly)

---

**Min – max time of meetings** (30 mins – 1.5 hours)

---

We agree to abide by our own code of practice and raise with each other when we have any difficulties with maintaining this commitment.

We agree that we will meet as scheduled above ending the mentoring relationship at the agreed time. We will undertake to honour all arranged meetings unless there is an unavoidable reason to cancel. We aim to give at least 24 hours' notice if we have to arrange an alternative date.

---

**The aim of the partnership is to work on the following issues/areas:**

a)

b)

c)

---

# Appendices

## Mentoring activities

(setting realistic goals, planning required actions, reviewing progress)

---

## Contact details

We **agree/don't agree** to exchange phone or mobile numbers to arrange/cancel meetings

---

We agree that the content of these meetings will be confidential.

---

The mentor will make brief notes of the meetings.

---

The mentor agrees to provide constructive feedback to the mentee. The mentee agrees to be open to the feedback.

---

We have discussed the basic principles underlying our mentoring relationship as a developmental opportunity. We agree to a no-fault conclusion of this relationship, if necessary.

---

**Mentee name**

---

**Date:**

---

**Mentee signature**

---

**Mentor name**

---

**Date**

---

**Mentor signature**

---

---

## Appendix III: Mentoring meeting notes template

Date

---

Location

---

Mentor

---

Mentee

---

Check in	How have things been?
1.	Make brief notes on the goals or aims agreed upon or on how progressing for goals already set. Omit any confidential details.
2.	
3.	

# Appendices

Item	Brief notes	Action
What do you want to work on for next meeting?		
1.		
2.		
3.		
Key learning or success		

Next meeting:

---



---

## Appendix IV: Nonviolent communication needs inventory

The following list of needs is neither exhaustive nor definitive. It is meant as a starting place to support anyone who wishes to engage in a process of deepening self-discovery and to facilitate greater understanding and connection between people.

### CONNECTION

acceptance  
affection  
appreciation  
belonging  
cooperation  
communication  
closeness  
community  
companionship  
compassion  
consideration  
consistency  
empathy  
inclusion  
intimacy  
love  
mutuality  
nurturing  
respect/self-respect  
safety  
security  
stability  
support  
to know and be known  
to see and be seen  
to understand and  
be understood  
trust  
warmth

### PHYSICAL WELL-BEING

air  
food  
movement/exercise  
rest/sleep  
sexual expression  
safety  
shelter  
touch  
water

### HONESTY

authenticity  
integrity  
presence

### PLAY

joy  
humor

### PEACE

beauty  
communion  
ease  
equality  
harmony  
inspiration  
order

### AUTONOMY

choice  
freedom  
independence  
space  
spontaneity

### MEANING

awareness  
celebration of life  
challenge  
clarity  
competence  
consciousness  
contribution  
creativity  
discovery  
efficacy  
effectiveness  
growth  
hope  
learning  
mourning  
participation  
purpose  
self-expression  
stimulation  
to matter  
understanding

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Website: [www.cnvc.org](http://www.cnvc.org)

Email: [cnvc@cnvc.org](mailto:cnvc@cnvc.org)

Phone: +1.505.244.4041

# Appendices

## Appendix V: Nonviolent communication feelings inventory

The following are words we use when we want to express a combination of emotional states and physical sensations. This list is neither exhaustive nor definitive. It is meant as a starting place to support anyone who wishes to engage in a process of deepening self-discovery and to facilitate greater understanding and connection between people.

There are two parts to this list: feelings we may have when our needs are being met and feelings we may have when our needs are not being met.

### Feelings when your needs are satisfied

#### AFFECTIONATE

compassionate  
friendly  
loving  
open hearted  
sympathetic  
tender  
warm

#### ENGAGED

absorbed  
alert  
curious  
engrossed  
enchanted  
entranced  
fascinated  
interested  
intrigued  
involved  
spellbound  
stimulated

#### HOPEFUL

expectant  
encouraged  
optimistic

#### CONFIDENT

empowered  
open  
proud  
safe  
secure

#### EXCITED

amazed  
animated  
ardent  
aroused  
astonished  
dazzled  
eager  
energetic  
enthusiastic  
giddy  
invigorated  
lively  
passionate  
surprised  
vibrant

#### GRATEFUL

appreciative  
moved  
thankful  
touched

#### INSPIRED

amazed  
awed  
wonder

#### JOYFUL

amused  
delighted  
glad  
happy  
jubilant  
pleased  
tickled

#### EXHILARATED

blissful  
ecstatic  
elated  
enthralled  
exuberant  
radiant  
rapturous  
thrilled

#### PEACEFUL

calm  
clear headed  
comfortable  
centered  
content  
equanimous  
fulfilled  
mellow  
quiet  
relaxed  
relieved  
satisfied  
serene  
still  
tranquil  
trusting

#### REFRESHED

enlivened  
rejuvenated  
renewed  
rested  
restored  
revived

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Phone: +1.505.244.4041

## Feelings when your needs are not satisfied

### AFRAID

apprehensive  
dread  
foreboding  
frightened  
mistrustful  
panicked  
petrified  
scared  
suspicious  
terrified  
wary  
worried

### ANNOYED

aggravated  
dismayed  
disgruntled  
displeased  
exasperated  
frustrated  
impatient  
irritated  
irked

### ANGRY

enraged  
furious  
incensed  
indignant  
irate  
livid  
outraged  
resentful

### AVERSION

animosity  
appalled  
contempt  
disgusted  
dislike  
hate  
horrified  
hostile  
repulsed

### CONFUSED

ambivalent  
baffled  
bewildered  
dazed  
hesitant  
lost  
mystified  
perplexed  
puzzled  
torn

### DISCONNECTED

alienated  
aloof  
apathetic  
bored  
cold  
detached  
distant  
distracted  
indifferent  
numb  
removed  
uninterested  
withdrawn

### DISQUIET

agitated  
alarmed  
discombobulated  
disconcerted  
disturbed  
perturbed  
rattled  
restless  
shocked  
startled  
surprised  
troubled  
turbulent  
turmoil  
uncomfortable  
uneasy  
unnerved  
unsettled  
upset

### EMBARRASSED

ashamed  
chagrined  
flustered  
guilty  
mortified  
self-conscious

### FATIGUE

beat  
burnt out  
depleted  
exhausted  
lethargic  
listless  
sleepy  
tired  
weary  
worn out

### PAIN

agony  
anguished  
bereaved  
devastated  
grief  
heartbroken  
hurt  
lonely  
miserable  
regretful  
remorseful

### SAD

depressed  
dejected  
despair  
despondent  
disappointed  
discouraged  
disheartened  
forlorn  
gloomy  
heavy hearted  
hopeless  
melancholy  
unhappy  
wretched

### TENSE

anxious  
cranky  
distressed  
distraught  
edgy  
fidgety  
frazzled  
irritable  
jittery  
nervous  
overwhelmed  
restless  
stressed out

### VULNERABLE

fragile  
guarded  
helpless  
insecure  
leery  
reserved  
sensitive  
shaky

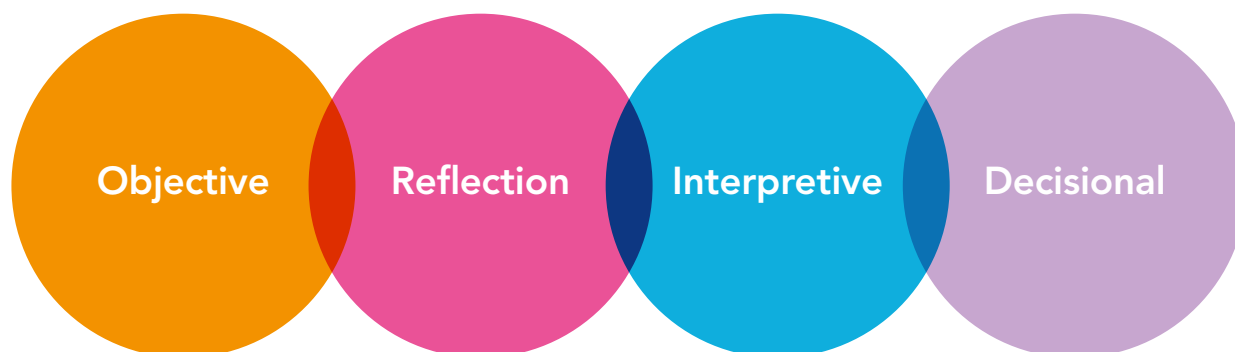
### YEARNING

envious  
jealous  
longing  
nostalgic  
pining  
wistful

# Appendices

## Appendix VI: Focused conversations

The focused conversations method is a questioning technique used in teaching and learning. This approach involves using a sequence of questions that progress in four stages. It can be used to take people from the surface of a topic to its depth and the implications for their life.



Type of question	Purpose	Example
<b>Objective</b>	Begin with data, facts External reality	"What did you actually see, hear or read, feel or taste?" "What stands out here for you?" What ... attracts your attention?"
<b>Reflective</b>	Access 'gut level' responses, associations, feelings, hidden images or stories associated with the facts"	"What was your gut level reaction?" "What does this ... remind you of?"
<b>Interpretive</b>	Draw out meaning, values, significance, implications	"What new insight did you get from this?" "What storyline are we living out?" "Is this significant to you?"
<b>Decisional</b>	Bring the conversation to a close and identify some resolutions or decisions	"What do you think we should do?" "What is your next step?" "When will you do that?"

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## Appendix VI: Discovering and sharing your story

This exercise was published in Action for M.E.'s Digital storytelling toolkit, which can be downloaded at [www.actionforme.org.uk/uploads/pdfs/digital-storytelling-toolkit.pdf](http://www.actionforme.org.uk/uploads/pdfs/digital-storytelling-toolkit.pdf)

The first thing we invite you to do is to spend some time thinking of the story of your illness. Here are some questions to ponder:

- When did you first become aware of your illness?
- What were the symptoms?
- What prior knowledge of the illness did you have if any?
- What were the effects on your everyday life?
- What emotions arose?
- How did the illness affect your relationships with others?
- What treatment did you seek and receive, if any?
- What's your current condition?
- Do you believe your illness is bringing you a message? If so, what insights have you gained?

When you're ready, we'd like you to find a trusted friend or partner (if working in a group) with whom you can share your story. Instruct your listener to simply listen not interrupt, to create a safe space for your story to emerge.

Your listener should not interrupt by attempting to "fix the problem," reassure you that everything will be OK, or over-empathise with you. It is OK, of course, to indicate or convey that they are interested and caring. And interruptions are acceptable if your partner doesn't hear you or requires clarification on something you said.

If working in a group with others challenged by the illness, you will also offer your partner an opportunity to share their story while you provide the listening. When you've finished, invite your partner to share what they heard by asking them to summarise the story so that you can be sure that they have heard you accurately.

At this point, you may want to take a break and write, draw or scribble in your journal, making notes and reflections on what you've said and heard. Note also how you feel at this point or sketch/make a note of any images, words, sounds that arise. These could be used later in the creation of your video.

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## Notes

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## Notes



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Keynsham  
BS31 1EH

Tel: 0117 927 9551

Email: [questions@actionforme.org.uk](mailto:questions@actionforme.org.uk)

[www.actionforme.org.uk](http://www.actionforme.org.uk)

   @actionforme

 @actionform.e

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Registered in Scotland no. SC040452  
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