

THIS TOOLKIT IS  
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# THE ESSENTIAL SELF- ADVOCACY TOOLKIT

DISCOVER HOW TO UNLEASH THE POWER OF  
YOUR VOICE, SPEAK UP, AND BECOME A FORCE  
TO BE RECKONED WITH IN TEN STEPS.

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# INTRODUCTION

In this toolkit, you will find tips and ideas to help you advocate for yourself. It has been created for anyone who has experienced or been impacted by pregnancy loss—particularly those with personal experience of not feeling heard when trying to get the services and information they need. The toolkit is full of tips and ideas to help anyone on their self-advocacy journey.ayah’s Legacy supports families who have experienced pregnancy loss and don’t feel they are being heard or that their views are being respected. The three steps to self-advocacy outlined in this toolkit can be used in every area of your life.

The three steps are:

1. Knowledge
2. Assertive communication
3. Self-awareness

The core principle of this toolkit is to be your own advocate, focusing specifically on bereaved families. However, the tools and approaches can help you speak up and be heard and respected in every aspect of your life. It asks professionals to understand and respect you and take your views seriously. It acknowledges that we can all get better at expressing ourselves and become more confident.

Self-advocacy—and this toolkit’s purpose—is for you to decide what you want, then develop and carry out a plan to help you get it. You can take control of your health and wellbeing and ensure that your approach is agreed on and supported by professionals you are working alongside.



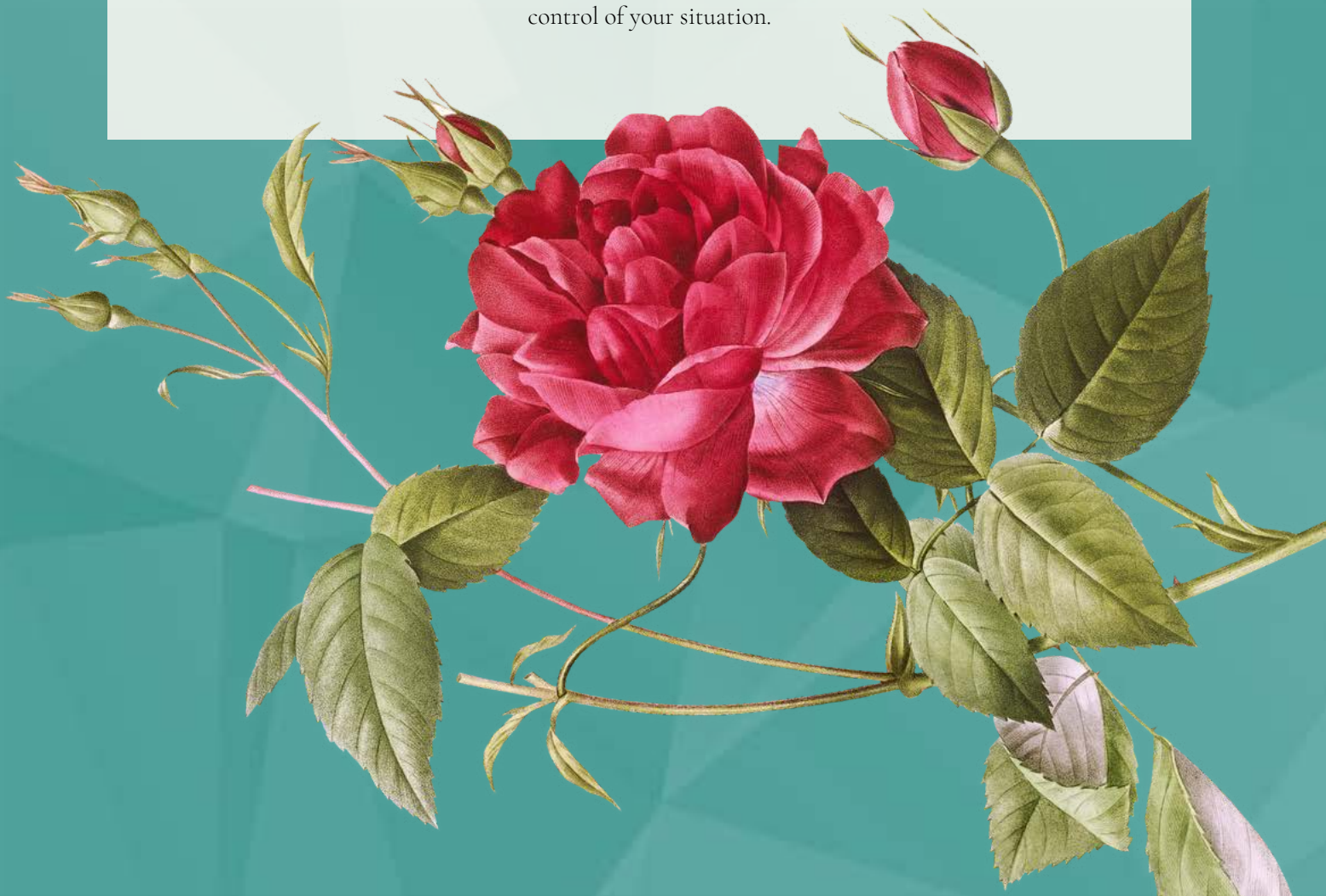
*You can take control of your health and wellbeing and ensure that your approach is agreed on and supported by professionals you are working alongside.*

# WHAT IS SELF-ADVOCACY?

When important decisions are necessary, self-advocacy means the ability to speak up for yourself and what's important to you. Self-advocacy means you ask for what you need and want and tell people your thoughts and feelings. It helps to empower you to direct your life.

Someone else can stand by you to help you understand your needs and the care you require and deserve. Advocates can also support you in making your own decisions, expressing your views, and being heard.

You are the expert in your life. You can express your wishes and feelings and take control of your situation.





## SELF ADVOCACY IS:

LEARNING ABOUT YOUR RIGHTS,  
LISTENING TO YOUR BODY, AND  
FOLLOWING YOUR INTUITION.

SPEAKING UP FOR YOURSELF SO  
THAT YOU ARE HEARD.

TAKING CONTROL AND MAKING  
DECISIONS ABOUT YOUR LIFE.

ACCESSING THE INFORMATION  
YOU NEED.

You are your own expert and should be involved in any decision that affects you. Sometimes, it can be challenging to speak up for yourself, especially if you don't feel confident, feel afraid, or cannot communicate in a way professionals understand. If you would like to learn how to advocate for yourself, this book will help you understand the three core principles of being your own best advocate.



# SUMMARY

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Self-advocacy is about gaining the knowledge, learning the skills, and developing the confidence to communicate your needs and what's important to you.

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## **KNOWLEDGE**

I will make sure I'm aware so that I can speak clearly for myself.

I will have a clear understanding of my issues and my goals.

I will ask you to avoid any unnecessary jargon so that I understand what you're saying.

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## **ASSERTIVENESS**

I will do my best to keep calm and listen to what you say. I also ask that you listen to me.

I will try to lead the process, as I see myself as the expert in my own life.

Every time I speak up for myself, I hope to build on my successes and failures to develop my self-advocacy skills and self-esteem.

I am aware that my personal experience might cause me to have prejudices about people, including the professionals involved in my life. Knowing this, I want to treat everyone fairly and respect that we all have different views.

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## **SELF-AWARENESS**

I ask that you are respectful and don't judge me.

I expect confidentiality.

I may wish to use self-advocacy tools, such as the Self-Advocacy Speaking Out Cards.

I am part of a wider network of people learning to speak up for themselves and will support others who are self-advocating.

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# KNOWLEDGE: FINDING WHAT YOU NEED TO KNOW

When people you don't know are trying to make decisions about your life, it's good to have as much information as possible about your situation or issue.

Whether you are preparing for a meeting with professionals or need to know more about your rights, you can find out by asking the people you are going to see.

1. See if they can provide you with more information. Big organisations like the NHS can also provide information in an accessible and easy-to-understand format. They should be able to tell you where to look or send you the information via email or post.
2. Look online – There is lots of available information if you know where to look.
3. Ask other qualified professionals – speak to people with experience in what you are going through.

## KEEP IT SIMPLE

We now know that the best way to learn new information is to pick out the essential parts— those bite-size pieces of information. But how do you know what is important to pick out? Whenever you are reading about something new or something you don't understand, write down the most significant bits that apply to you. It can be tricky holding onto knowledge and information to use it and understand it.

You might want to make bite-size points about the topics you need to know about and how they apply to you. Don't write big stories; keep them short and to the point. This also helps you remember it.

## USING THE INFORMATION

Use the information to help you to self-advocate. This part takes practise, and you might not be able to do this the first time you try, but don't give up!

Remember that self-advocacy isn't about doing it on your own. You can use support organisations or other resources. However, the more you can do for yourself, the better.

Self-advocacy is about using your knowledge, assertiveness, and self-awareness to make your voice heard. This toolkit can help you get started, and each time you self-advocate, you will improve and learn something new.



*When people you don't know are trying to make decisions about your life, it's good to have as much information as possible about your situation or issue.*

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## WHAT IS ASSERTIVE COMMUNICATION?

Now that you know how to access information and build your knowledge, we need to look at the skills you need to self-advocate.

Being assertive reduces stress and improves your communication skills.

Being assertive is a core communication skill. Assertiveness can help you express yourself effectively and stand up for your point of view while also respecting others' rights and beliefs.

Being assertive can also help boost your self-esteem and earn others' respect. This can help with stress management, especially if you are going through a tough time and have difficulty saying no.


You can disagree, and you can say no, but make sure you do the following to help ensure you get what you want to say across:

- Listen to what others are saying.
- Don't rush; say what you need to say.
- Consider the options; if they aren't acceptable, say why.
- If you disagree or need to say no, do it. Give your reasons and be clear about these.
- Try to keep calm.
- Don't feel you can't say or question something.

Being assertive shows that you respect yourself because you're willing to stand up for your interests and express your thoughts and feelings. Being assertive is usually viewed as a healthier communication style. Assertiveness offers many benefits, including stopping people from taking advantage of you.

Behaving assertively can help you:

- Gain self-confidence and self-esteem
- Understand and recognize your feelings
- Clearly communicate what you want or set a boundary
- Show respect for everyone involved
- Improve communication
- Create win-win situations
- Improve your decision-making skills
- Create honest relationships.



*Being assertive shows that you respect yourself because you're willing to stand up for your interests and express your thoughts and feelings.*

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## **Q U E S T I O N S**

**WHAT ARE YOUR BIGGEST  
STRENGTHS?**

**WHAT ARE YOUR BIGGEST  
WEAKNESSES?**

**WHAT ARE THREE THINGS THAT  
YOU DO WELL IN YOUR SELF  
ADVOCACY?**

**WHAT ARE THREE THINGS THAT  
YOU NEED TO IMPROVE IN YOUR  
SELF ADVOCACY?**

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# PREPARING FOR MEETINGS, PHONE CALLS, EMAILS, OR LETTERS

Preparation is the key to a successful meeting, phone call, email, or letter. You need to be sure that you outline the most important things about the issue that you want to sort out. Avoid telling a story; think how you can be concise in clear in your communication about the issue.

To be well-prepared for a meeting, think about the following:

- To whom am I speaking?
- How many people will be there?
- Do I need someone with me to support me?
- What is this meeting's purpose?
- What do I need to say?
- What do I want from the meeting?
- What can I be flexible on, and what can't be changed?
- What's next if things don't go well?
- What information do I need?

Remember, any meeting about you is your meeting. So, it needs to be easy for you to understand and clearly outline the results and what you can expect next.

## HOW TO HOLD A MEETING

Preparing for a meeting is important. With good preparation, you can get the most out of the meeting and not feel like you missed an opportunity to be heard and understood.

Meet somewhere comfortable and safe so that you feel at ease with discussing what you need to discuss. A meeting might be in your home, at an office, or at your doctor's surgery. If the meeting can be held in a place that makes you feel more comfortable, like your home or somewhere you know well, you have the right to ask for that.

Find out who is coming to the meeting and why they are there. You can ask people not to come if they upset you or find it hard to meet them. This might mean the meeting will have to happen at another time. You can ask to arrange a meeting to discuss your health and aftercare needs with a professional.

Meetings don't have to be stressful, but they can be. If you need someone with you, make sure to arrange your meeting at a time when they can come.

Take a break if necessary. It is important that you feel in control and can stay calm and collected; this will enable you to listen and speak up for yourself. If you find yourself becoming stressed or uncomfortable, ask for a break, get a drink, go to the toilet, or get some air outside. Think about what you need to do next and refer to your notes if you need to. Take your time, take a break, and don't be afraid to ask if you need more information or don't understand.

Formal meetings nearly always go like this:

1. There is a meeting chairperson - This is who keeps the meeting on track.
2. Introduction - People introduce themselves and explain why they are there. The meeting chair discusses about what the meeting is about.
3. There is an agenda of what will be discussed in the meeting.
4. Everyone will get a chance to speak about each issue on the agenda.
5. A decision may need to be made; this is usually after everyone has spoken.



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# COMMUNICATION SKILLS

Communication is how you get your message across and listen to what someone else is saying. Communication can go wrong when these two things aren't done right.

## GETTING YOUR MESSAGE ACROSS

Some people find it hard to speak up, which can make communication more difficult. If you do have a barrier to communicating, it is important that you let people know what you need to be heard. Make sure that anyone meeting with you understands your communication style and is prepared to communicate in the way you need.

This could be asking someone to speak without jargon (plain English), using text on a phone, using email, or meeting in person. Use whatever tools you can to communicate effectively and impact fully, however you communicate.

Communication is much more than what we say; your body language can also communicate how you feel; something like a simple nod or a head shake can sometimes communicate more than words.

## LISTENING

Listening is an important skill. Good listening skills helps build relationships, solve problems, ensure understanding, and reduce upset or distress.

This is about you so if you come away confused, don't be afraid to ask for clarification—see if the information can be explained again or differently—or a follow-up meeting.

Concentrate and listen to what the person is saying. Ask for time to think if you need it. Take your time. You can repeat back what someone has said to make sure you understand.

## TIMEKEEPING AND GOALS

Time is the limiting factor in many meetings. Most people have limited time and long to-do-lists, making timekeeping even more important. If someone is late for a meeting, you may not have enough time to get your message across.

Timekeeping for a meeting isn't just about making sure people are there on time; it's also about knowing:

- How long you've got to discuss your issue
- How much time you need for each item on your agenda
- If you'll have the opportunity to have a break if required or go to another meeting

## How long?

How long is the meeting scheduled for? Ask this when the meeting is arranged. If you know how long you have, you know what type of schedule to keep to make sure that you say all the things you need to. That way, nothing is rushed, and you allow yourself enough time to say what's important to you.

## How much time do you need?

Before and during the meeting, think about what you want to talk about—what's most important and what can be moved to another meeting (or call or email) if you run out of time. Some things may need more time than others. For example, finding somewhere to live is more complicated and may take more time than finding voluntary work.

- Be clear about what's important
- Make sure you have enough time
- Keep the meeting on track – stop and redirect the conversation if people talking about other things that aren't important
- Have you got enough time to talk about everything you need to?
- Ask for a follow-up meeting if needed



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## LEARNING HOW TO NEGOTIATE

Negotiating is about trying to get your desired outcomes while listening to and accommodating (to some extent) the other side. It is about more than one person agreeing on what is possible. Negotiating can be the difference between getting what you want and missing out on the chance to get it.

When negotiating, decide what conditions are most and least important to you. This will help if you need to make allowances to come to an agreement. Don't be afraid to ask for what you want; to do this, it may help to make a list of those things. Rank your conditions on their importance, with the most important being at the top of the list and the least important at the bottom.

## NEGOTIATING

When negotiating, you might find you need to come to a compromise. This could mean that not everything is possible. Coming to an agreement means having to sometimes sacrifice everything you want for a solution that can satisfy and accommodate both parties.

Can your conditions be changed? Is there a different way to get what you need that you might not have thought of? Can you settle for less than you want?

If the compromise is completely different, will it change things for you?

It's important that you:

- Listen to what is being said.
- Think about what the difference means for you.
- Ask for more time if you are not sure. Don't agree until you have had a chance to think about whether this agreement is right for you.
- Ask questions about things you are unsure of or ask if there are other options.
- Only agree if you are sure that it's right for you.
- If you are unhappy, raise this feeling. You can always make a complaint later on.

## HOW TO CONTROL YOUR EMOTIONS

Keeping your emotions in check ensures that the focus is on what you have to say and what you want. Sometimes, being emotional just can't be helped; emotions can't just be switched off. We can learn to control them a little to avoid getting upset or angry. Sometimes, we may later regret saying or doing things in anger or frustration.

The key to learning to control your emotions is finding a way that helps you to stay calm. There are a lot of different ways to do this:

- Play with something in your hands, such as a stress ball
- Controlling your breathing can help; take slow, deep breaths
- Think of something you really like or that makes you really happy
- Ask for time to think or take a break
- Close your eyes and gather your thoughts for a moment
- Think about what you want to say before you say it

These tips aren't a guarantee that you will be able to check your emotions. We are only human and cannot always control how we react. However, remaining calm and giving yourself time to think about your response will help you. You know yourself best, so try and practise what makes you feel happier or calmer. Again, like everything, practice makes you much better at it.

There are times when other people can get upset with you, through no fault of your own. Emotions can sometimes run high, and people can get upset or angry.

The following tips may help you avoid conflict should the situation arise.

- Ask for a break. Sometimes, a timeout can help calm a situation down. Everyone feels refreshed after a break.
- Stay calm. This can be really hard if someone is upset. Try to practise what makes you feel calm, as we explored earlier on.
- Don't make it personal. Emotions run high if people feel personally attacked. Make sure you talk about the issue, not the person. Try not to make personal comments about someone else.
- Remind others to stay calm. If someone gets upset or angry, it's much easier for others to do so, too. Try to stop a situation from escalating by asking people politely not to raise their voices.
- Listen to how someone feels; you don't have to agree with them, but accept their feelings.
- If someone says something that you disagree with, let them finish. Then, consider how you want to reply. Speaking over people can make them upset or angry. Waiting to speak is important and gives everyone a chance to have their say and their voices heard.



## HOW TO WRITE UP NOTES

Note-taking can be a difficult skill to learn; if you write too much, you might miss what is being said. If you write too little, you might not document the important information you need.

Not every meeting will require you to take notes; it is up to you. Some official meetings may have someone to take notes and distribute them afterwards. In other meetings without a professional notetaker, you may want to write these yourself. This part of the toolkit will help you to make notes to remember what was said whilst still taking part in the meeting.

There are a few different ways to take notes; which one works for you is a matter of choice.

## IMPORTANT WORDS

Some find that it helps to note down important words. This can help you remember what was being talked about and helps you remember the most important parts.

## SHORT SENTENCES

If you have time to write down more than just a word, make a short sentence about the part you wish to remember. Again, this makes sure you only record the important parts.

## USE HEADINGS OR TITLES

If you are discussing more than one point, use a heading or title to break up your notes. This helps to organise your notes and jog your memory. Make sure you put the headings in order of the points discussed.

## USE A DATE

This will help you remember what was discussed and on what day.

## HAVE SOMEONE ELSE TAKE NOTES FOR YOU

Someone can support you at the meeting to take notes for you.

## FOLLOW UP FROM A MEETING

There may be actions items that need to be done by others from the meeting after it has finished. There might also have been an agreed-upon time limit, date, or deadline for when these actions need to be completed by.

If you have taken notes, make special note of any action items. You can record actions using the following outline

- The action item
- Details of what needs to be done
- Who is going to do it?
- When should the action be done by? (Deadline)

If you have the details written down in an easy format, like shown here, it will be easier to follow up. If you don't hear about any actions by their completion date, contact the person who should be doing them. If the action is not completed, make sure you agree on a new deadline.

This shows why it is important to make notes and have a record of who is doing what and by what date. You will always know when things should be done by and are able to follow up if things are late or have been missed. If the actions you noted down need to be completed for the next meeting, then you will not need to follow these up. Simply make a note to ask about them next time.

## MAKE A NOTE!

- ✓ *The action item*
- ✓ *Details of what needs to be done*
- ✓ *Who is going to do it?*
- ✓ *When should the action been done by?*
- ✓ *Anything else important!*



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# SELF - AWARENESS

Self-awareness is our ability to observe and accurately identify our thoughts, feelings, and impulses, and determine if they are grounded in reality. One of the most important things to remember throughout this whole process is to be kind to yourself. It's so much easier to help someone else and ignore the most important person—you.

Personal growth comes with its own share of mistakes and lessons learned from them. Understanding yourself and what you need to maintain your mental and emotional wellness is key to self-awareness. Practicing self-awareness is about learning to better understand why you feel what you feel and why you behave in a particular way. Having this awareness gives you the opportunity and freedom to change things about yourself, enabling you to create the life that you want. It's almost impossible to change and accept yourself if you are unsure of who you are. Having clarity about who you are and what you want can be empowering, giving you the confidence to make changes.

Benefits of Self-Awareness:

1. Aids self-control, creativity, pride, and self-esteem
2. Predicts self-development, acceptance, and proactivity
3. Facilitates decision-making
4. Leads to more accurate self-reports
5. Required to develop self-control

You may get frustrated along the way, but this happens to everyone. Feeling upset or angry at yourself is natural; remember to look back on how far you have come. Use your friends and family to talk about your journey. You can even speak to professionals to find out how they do things, they have all been where you are.



Be  
KIND  
TO YOURSELF

The background of the entire page is a dense field of small, light pink flowers, possibly phloxes, with a soft, slightly blurred effect. A semi-transparent white rectangular box is centered on the page, containing text and a red rose illustration.

## TAKING CARE OF YOURSELF

Being able to keep going and take the knocks is easier if you are looking after yourself. Make sure you take care of the person at the centre of this whole process—you. Think about your mental and physical wellbeing. Here are some tips for taking care of yourself.





## TIME

Giving yourself time to get things done is really important. If you have a lot to do, you may need to think about how you are going to do them without feeling rushed or overwhelmed. Write a list, make a schedule, and think about what time of the day you work best and even where you work best.

## LEARN TO SAY NO!

You can't do everything—no one can. Only take on what you can manage and don't be afraid to say no. You have to put yourself first.

Taking on too much can cause you to become stressed and rush things. Sometimes, when we say no, it can feel like we are letting people down, but it is often necessary to let people down to look after our own wellbeing. We are not superhuman and can only do what we can. Taking on too much can negatively affect everything else you do.

Most of the time, people will understand!

## EAT, DRINK, AND BE CONTENT

Make sure that you have enough to eat and drink and make plenty of time for breaks. A full stomach ensures you have the fuel and energy you need to get things done. If it helps, aim to do a bit of work and treat yourself when you get there. For example, once I get this letter done, I'm going to have a cup of tea and a biscuit.

## BE IN THE MOMENT

Do something that isn't active. Make a hot drink, sit at your window, watch the world go by in a café, or switch your phone off and be in the moment. You can do this for a few minutes or a few hours—however long it takes to feel the effects. Switch off and appreciate the things around you.

## SLOW IT DOWN

Do the important task, take a break, take a deep breath, and get ready for the next thing. Don't rush; you will find that you will actually get more done and do it better when you haven't tried to cram too many things in. Work at a pace that makes you feel productive but doesn't tire you out. Look back at your progress—remember the story of the tortoise and the hare? Who won in the end?





## **BE POSITIVE – EVEN IF YOU DON'T FEEL IT**

Try to find the positive in your life and the world around you—whatever that is, your food, your house, your day, your kids, being in the countryside, reading a lovely story. There are amazing things happening in the world if you just take the time to see them. This isn't about ignoring the bad or hard things; it is about finding one small part that is good and then perhaps looking for one or two more. Humans are wired to look for danger; it's how we survived thousands of years ago. We forget the nice things because they aren't a life-or-death matter. We are lucky not to live like that anymore. Find and remember the good things—it will make you feel more positive.

## **IT'S OK TO FEEL**

Acknowledge your feelings; let them come, but try not to dwell on them or overthink them. Don't fight feelings or try to hold on to them. By doing this, we accept how we feel about something now or in the past. We allow the feeling to happen, and we allow it to go away.

By not dwelling on the feeling, we aren't becoming stuck.

## **DO SOMETHING FOR YOURSELF**

Find something to do just for you. This could be anything that brings you pleasure and makes you feel happy. It could be a walk or a bit of time outside. You could read a paper or watch a comedy movie. Go for a drive in the country, take a bath, or bake a cake. Take time to pamper yourself.

## **DO SOMETHING FUN**

Remember that feeling when you were a child? The zest for life and awe you had for new and exciting things? Life is meant to be enjoyed.

That's up to us, and only us. Make the best of the life you've been given. Do things that put a smile on your face. Laugh with friends, play games, or do something active; try and get back that childlike feeling back.





## GO OUTSIDE

Walk, sit, or just watch the world go by. Being outside connects us with nature and people. Whatever keeps you in contact with the world. Whether it's the countryside, your local village, or town centre, just be part of it all. Speak to people, listen to the environment, hear the birds. For many people, being outside with nature brings a sense of peace.

## REWARD YOURSELF

The reward can be anything you would look forward to and find special—your favourite meal, visiting a friend, going for a picnic, or a day out.

## MEDITATE

Give yourself five minutes to just sit, no TV, no phone or internet. Clear your mind of any thoughts. Five minutes is quite a long time to sit and do nothing. This can help some people relax and focus. The distractions in our lives can be tiring and exhausting; a timeout can help us recharge our batteries.

## BE PROUD

Keep a record of what you have done and your successes. Write a list of what you are grateful for and what you have going for you. It might be your health, family, friends, how good you are at art, or how funny you are. We often forget the good things and don't celebrate our success, so remind yourself of all the wonderful things you have.

## CONTACT PEOPLE YOU MISS

Did you lose contact with a childhood friend or someone you got on with because life got busy? Talking about the past helps us connect with who we are. Other people can bring up happy memories and remind us of how far we've come. Reach out and start a conversation. If you have lost touch, there are many ways you can find people, such as using social media.





## MAKE IT A LITTLE SIMPLER

Don't try to have too many things on the go. When we have too many plates spinning at one time, we will often drop one of them. If we give ourselves less to do, we can focus on getting them done before tackling the next thing. This is called prioritising. Focus on the most important things that need to be done now and leave the rest until later. Trying to do too many things at once might mean nothing gets done or that you'll make mistakes. Keep it simple, do one thing at a time, and you'll find you actually get more done.



# SELF ADVOCACY 101

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01

Try to view your situation as something you can change and take control of;

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02

Before any conversation or meeting, preparation is key. You are the expert on your own life and know what's best for you. Sometimes, people will think they know better, and you will disagree. It's important to remember that nobody knows you better than you do;

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03

Have a clear plan for the issues you want to raise and the best way to communicate them;

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04

It's good to help others, but not at the expense of your own health and wellbeing. Self-care is very important and can improve your mental, emotional, and physical health. It can also reduce anxiety. Once you've mastered good self-care, you're in a better position to help others;

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05

You may not always feel able to self-advocate. There is support out there for you, whether it's a family member, friend, community support group, professional advocacy, or online resources. Don't be afraid to seek help. Ask someone you feel comfortable with to get the ball rolling for you;

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06

People don't need to know everything about you, just what you need them to know. Make sure you clearly voice your concerns, wants, and needs so people can help you to the best of their ability. If people don't understand you the first time, think about a different way of describing what you're feeling and what you need;

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07

Don't end a conversation with a professional until you're sure you've understood everything they've told you. If you don't understand something, ask;

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08

You need to work out what's important to you. Can you compromise on your needs or wants? Can professionals? Write down what you can and can't change and begin to negotiate if you can't reach your desired outcome;

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09

Speaking up for yourself can be hard, but remember to keep going. As you practise your new skills, your confidence will grow. You may have the odd setback, but don't let this stop you. Confidence needs time to grow; be kind to yourself and allow it to happen naturally;

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10

Body language speaks louder than words. Your body language shapes people's perceptions. Seventy percent of any given conversation is non-verbal. That's why it's important to be aware of your body language and vocal tone.

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**MAYAH'S LEGACY**  
YOUR HEALTH. YOUR WELLNESS. YOUR JOURNEY.

**FURTHER HELP AND SUPPORT**

If you have a question about this toolkit or need more information about self-advocacy, please get in touch at

[info@mayahslegacy.com](mailto:info@mayahslegacy.com)  
[www.mayahslegacy.com](http://www.mayahslegacy.com)