

A Guide to Self-Advocacy for those with long-term Neurological Conditions

advocacy

to change “what is”
into “what should be”



*Living better with
self management*

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1. Introduction

Fairway Advocacy wishes to thank the Alliance (Health and Social Care Alliance Scotland) for providing the grant, to create this guide, from their IMPACT fund. We also are indebted to the organisations, organisers and attendees at the workshops so- instrumental in guiding us on the contents of this document. Individuals and their organisations are acknowledged at the conclusion of the Guide. Whilst this booklet is directed for and shaped by those with neurological conditions, it is hoped that it will be equally applicable to those with all long term physical conditions for whom statutory access to professional advocacy services is denied by law.

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What is Self-Advocacy?

'It is an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs and rights. It involves making informed decisions and taking responsibility for those decisions'.

The Three Steps to Self-Advocacy are:

1. Knowing that you are a "learner"
2. Doing what you need to advocate successfully
3. Communicating your needs to those who need to know them appropriately

Self-Advocacy:
Know Yourself,
Know What You
Need, Know How
to Get It

Why is this Guide Necessary?

Independent Advocacy has been established in Scotland for over 20 years and statutory access (for those who are entitled to it by law) is defined by The Mental Health (Care & Treatment) (Scotland) Act 2003. **This gives every person with a mental or learning disorder a right to an independent advocate.** The Act does not, however, cover those with neurological or other physical conditions for whom no statutory funding is available and access is limited. Statutory funding means that the Local Authority has to provide funding for professional advocacy services.

If persons with neurological (or any physical conditions) are not entitled to the help of a professional advocate (and there are over 80 advocacy services across Scotland) then the only way that you can have your voice heard is by learning to be your own advocate.

How was the Guide Developed?



Workshops

Guides and information documents in health care are more often compiled by “the experts” and compromise of what the experts feel the individual, for whom the guide is written, should know. Such guides, whilst well intentioned, are often full of jargon and not always of value to the intended audience. **We have tried to get around this by having our guide’s contents defined by persons with neurological conditions.**

Twelve workshops involving over 80 persons have helped create what follows.

At each workshop we presented a plan of contents and then heard from individuals themselves what they themselves felt were the most important areas that should be covered to allow each to advocate on their own behalf. This guide is therefore not the information that we originally intended but rather the information that we were asked to provide by workshop attendees. To this end we thank the service users of MS Revive, MS Society,

Headway, Epilepsy Connections, the Brain Tumour Charity and the Glasgow Disability Alliance. This guide is the result of the input and advice provided by them and to them the Guide is dedicated.

The case studies that we have included are based on true experiences and comments made at the workshops. Names and some facts have been altered so that the stories remain anonymous and confidentiality is preserved.

2. The Basic Facts.



> What does advocacy do?

- Helps a disadvantaged person voice their concerns, views, beliefs, opinions to those in authority
- Ensures that these are taken into account during decision making processes
- Encourages the client to participate in the decision making processes
- Makes others aware of their rights, entitlements and options available to the client
- Helps clients access their entitlements
- Ensures that rights and entitlements are not infringed upon
- Ensures a “level playing field” between client and an authority

> What are the different types of advocacy?

TYPES OF ADVOCACY

- PROFESSIONAL / PAID ADVOCACY
- SELF ADVOCACY
- PEER ADVOCACY
- CRISIS / SHORT TERM ADVOCACY
- CITIZENS ADVOCACY

• PROFESSIONAL / PAID ADVOCACY.

Many people advocate as part of their professional role. Examples of professionals who provide advocacy as part of their role are: doctors, nurses, social workers, occupational therapists, speech and language therapists and lawyers. However, there are times when these professionals cannot provide advocacy as it can conflict with their professional interests. An Independent advocate is separate from the above and represents the client only. Professional paid advocacy is only available to those with mental health and learning disability and not to those with neurological (or any physical) disability.

• SELF ADVOCACY – this is you!

This is when a person speaks up for themselves. This can be in a variety of settings for example, a person making a complaint about the attitude and reception they received from a member of bank staff; a patient demanding a second opinion or someone independently voicing their own concerns, beliefs, values and wishes at a social work review meeting.

• PEER ADVOCACY.

This type of advocacy involves a person who is a member of a group, elected by its members, speaking up for the interests of all the group members. Such groups may be made up of people who share a common issue such as a disability. An example of Peer Advocacy would be someone who is a member of a disability group speaking to a Member of the Scottish Parliament about lack of disability access to public buildings in their local community on behalf of that group.

This involves advocating for people during moments of crisis or short term stressful situations. Examples of Crisis Advocacy would be advocating for someone when the bailiffs are coming round to that person's home or assisting someone who has been threatened with eviction.

Citizen advocates are volunteer advocates that are independent of the services they are dealing with, as well as having no conflicts of interest that could affect the partnership between advocate and client.

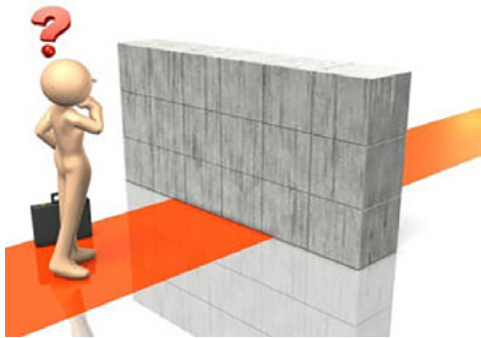
An individual's right to access paid professional advocacy is set out in the Adults with Incapacity (Scotland) Act 2000, Mental Health (Care & Treatment) (Scotland) Act 2003 and re-enforced by the Scottish Government's 'Independent Advocacy': Guide to Commissioners December 2013. **Currently those with long term neurological conditions have no statutory right to independent advocacy thus statutory funding is unavailable to organisations wishing to support them.** Whilst Advocacy organisations throughout Scotland will make the effort, when possible, to see people with neurological and physical conditions such work is 'unfunded'- the advocacy organisation is not paid for the work done. As a result, only a very small number of people with these conditions are supported by a professional advocate irrespective of the urgency and need of their situation.

[illegible]

The Neurological Alliance of Scotland (NAS), launched in 2004, estimated that about **100,000 Scots are disabled by a neurological condition**. Neurological conditions are poorly understood, discriminated against and often take the form of an **unseen disability** (epilepsy, early multiple sclerosis and dementia) in that there is nothing for the onlooker to see. The needs of people with these conditions are often misunderstood and decisions, regarding their life choices, are frequently made by those in authority (e.g. social work, housing, employer, educator etc.) with little understanding of the nature of the illness being dealt with.

This self-advocacy guide is aimed to help many for whom ‘fighting the system’ alone with low confidence and low self-esteem, has previously proved too much for them. It is to this group that the guide is directed though hopefully those with other physical conditions might also find it valuable.

3. What are the “blocks” to successful self-advocacy?



By knowing what we are doing wrong we can make the necessary adjustments for the best chance of success.

Many of the obstacles that can get in the way of self-advocacy are what we call ‘**cognitive**’ in nature. Anything that relates to the **mind/emotion connection** can be described as being ‘cognitive’. You may have heard of **cognitive behavioural therapy** (CBT) which is a treatment that uses the mind to address mental health issues that are largely problems related to emotions and attitude. These emotions can have a huge impact on the quality of our lives as well as the fulfilling of our potential and speaking up for ourselves.

Many of us are capable of being a very good self-advocate but we require another person to help us as our potential to speak up for ourselves has been ‘hijacked’ by our emotions. The kinds of emotions and attitudes that can ‘hijack’ our ability to advocate for ourselves are emotions such as:

Anger, fear, apathy (low mood), despondency, low self-belief, cynicism, low morale & self esteem, loss of faith in Humanity, procrastination (due to forecasting a bad outcome), **over inflated opinion of others** (those of higher status to ourselves), **excessive pride**.

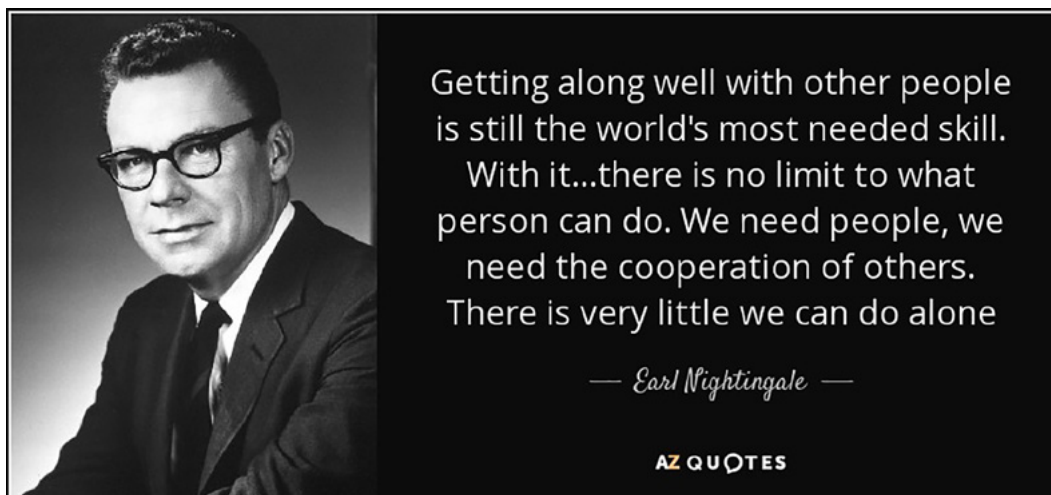
These emotions will affect the way we communicate with others especially those who play decision making roles in our lives such as: **Social Work, Housing, Medical /Social Care Professionals, Employers, Educators, Care Providers, Police, Local Authority Departments & many more.**

At times we may find ourselves needing to liaise with professionals who work for one of these authorities. They may be making key decisions that will affect the quality of our lives for the long term. We will want the best service that these professionals have to offer us and what we feel entitled to. For Example:

- A stair lift put into your house
- A home away from troublesome neighbours
- A better Care Provider who can put you to bed at a time appropriate for you rather than convenient for them
- An employer to take necessary action in response to claims made by you about bullying and disability discrimination

You want to be actively involved in the decision making process and you will want to present your case for your rights and entitlements to the best of your ability.

“Amicable relationships with the people you deal with are the key to successful self-advocacy.”

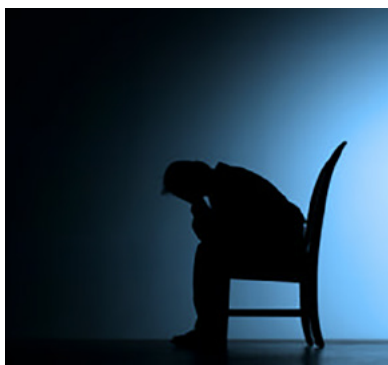


A key factor in trying to obtain from an authority the service, or action that you wish, will be the forming and keeping of friendly, amicable relationships with the professionals involved. This will require you to not let emotions such as **anger, cynicism** (believing that people are motivated purely by self-interest) **and excessive pride** influence the way you communicate.

- If you get angry you intimidate.
- If you are cynical you will be disliked.

If you let anger, pride and cynicism affect the way you interact with these professionals you will very likely appear intimidating and cause defensiveness and a lack of co-operation from those you intimidate. This will make you unpopular. Professionals will feel negative towards you and say **“Oh no, not him/her again”** when you are next about to meet them. They will start avoiding you and your issues will remain unresolved. Professionals often take a lot of abuse, on a regular basis, and are human. Your attitude may allow their emotions to determine their decisions and result in you getting a poor deal. **By remaining amicable and being liked you come away with a much better chance of the result you wished for.**

“Don’t get despondent”.



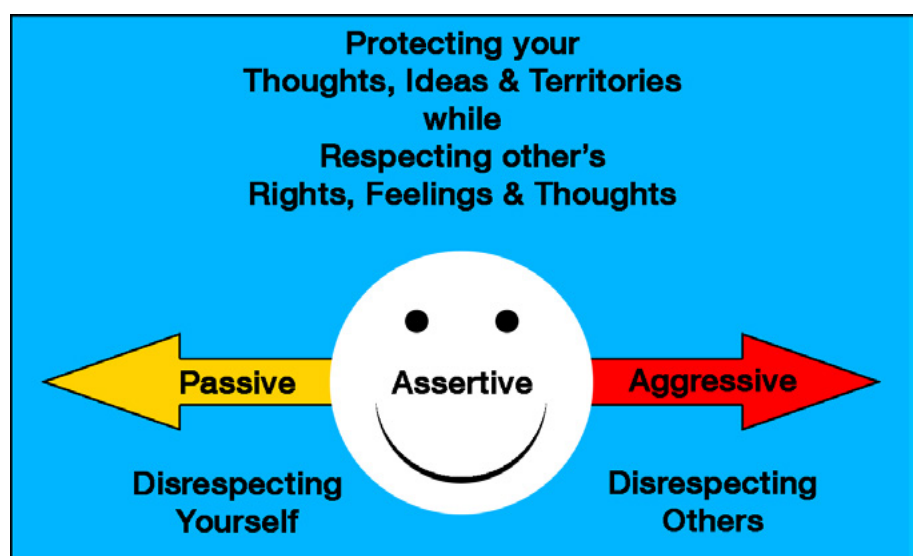
Despondency is a state of low spirits caused by a loss of hope or courage. It is important that you don’t let **despondency** affect you when meeting with these professionals as this will impair your efforts to get the best deal for yourself. People who are despondent do not give their efforts 100%. Anyone not giving their efforts 100% performs below par and will not give a good account of themselves or their case. By remaining **optimistic** you will remain inspired and motivated to put your best efforts into self-advocacy thus getting for yourself the best possible outcome.

It is also important for you to not let **low self belief** affect you as this results in negative self-talk; this only convinces you into believing that you are not capable of adequately advocating and that this will lower your confidence. A lack of self-confidence will be obvious at any meetings or come across in phone calls. Low confidence will affect your **assertiveness** which is an important attribute in addressing the issues that require the cooperation of a person or party with authority to resolve. If you appear **unassertive** you will give the impression that you will **settle for less** than the service/facility/action that you are entitled to. You might accept a lesser service that is more suited to the budget of the service-provider than to yourself.

Despondency and low self belief are some of the feelings felt by those with depression. Advice on recognising and managing depression can be found at: www.nice.org.uk/guidance/CG90

“Be assertive but not aggressive”.

Many people nowadays use the phrase **“loss of faith in humanity”** and this mantra convinces them that those managing social welfare budgets **“put savings before people”**. They feel no matter what they try to do, to get the best service for themselves, they will never achieve this as those they are negotiating with **“don’t care about me and they are only interested in saving money”**. Basically this means that the individual has lost confidence in people (in this case the decision makers) and no longer believes that those in authority are capable of making ethical and moral judgements. This attitude can produce further **cynicism** and results in you not giving self-advocacy your best attempts or even prevents you from trying to self-advocate at all. You end up saying **“what’s the point?”** but what you are really doing is denying yourself the opportunity to make things better for yourself.



“Don’t procrastinate”.

Procrastination is the avoidance of doing a task which needs to be accomplished. In self-advocacy the tasks affected could be

- Making a phone call
- Writing a letter
- Attending a meeting

Many people **procrastinate** when they see, in their mind’s eye, meetings with the professionals going badly wrong. They don’t believe that they can self-advocate and are convinced that any attempts to self-advocate will fail. **It is the avoidance of the failure that they are expecting that causes the procrastination.** As a result people either don’t attempt to self-advocate or, if they do, all their efforts are destroyed by expectations of things going wrong. **Procrastination** causes anxiety which affects **assertiveness** that then silences the self-advocate in you. It becomes a vicious circle as all our emotions are linked with one leading to the next.



“Don’t feel inferior”.



Not seeing professionals as ordinary people has a negative effect on our ability to self-advocate. Too often we say to **ourselves** “**Who am I to tell him I what I want, he is a doctor and I’m just an ordinary person**”. Statements like this are frequently said in the minds of people trying to resolve an issue/dispute with professionals. Thinking like this only puts you down and, if said often enough, will convince you into believing that you are ‘small and insignificant’ in comparison to the professional with whom you are dealing. You become convinced that the professional is ‘bigger’ than you and therefore you never challenge the decisions that they make for you. You have become passive and disempowered. This **inferiority complex** affects your self-confidence, fills you with anxiety and fear and impairs your ability to self-advocate.

Advice on managing an inferiority complex can be found at: www.wikihow.com/Get-Rid-of-an-Inferiority-Complex

Key Points

- Identify you own “blocks” to self-advocacy
- Always remain amicable never threatening
- Always be assertive but not angry
- Avoid putting things off till tomorrow (procrastination)
- Respect your professional but don’t put them on a pedestal above you– they are human like you

4. Cognitive techniques to empower the self-advocate within ourselves:

This section aims to answer the question: How do we prevent emotions and attitudes from affecting our ability to self-advocate? The answer to this question is: Through the use of cognitive techniques. Some of these techniques are discussed in greater detail in the concluding section of the guide.

Anger.



There are two types of **anger**. **Chronic** and **acute anger**. Chronic anger is anger that we live with 24 hours a day, 7 days a week. Acute anger is what we experience at the moment something irritates us: being talked to in a way that we do not like; being told something we don't want to hear; or having our car bumped at the supermarket.

Both types of anger can impair the self-advocate within us. Chronic anger, anger that we feel all the time, make us get into arguments and fights with people. Acute anger causes us to have sudden outbursts with people and are often part of our '**mood swings**'. To experience both these types of anger at a meeting with professionals, or when speaking to a professional over the phone where the aim is to find the best resolution to an issue, will jeopardise your chances of success; so, it is very important for you to learn to manage anger.

Our thoughts are what make us chronically angry. Our emotions are created by our thoughts and our emotions dictate our behaviour. If we have angry thoughts throughout the day, we will feel angry throughout the day, making us very likely to behave in an angry way if something upsets us. Those of us, who don't have angry thoughts most of the time, do not feel chronically angry and so, will be less likely to behave in an angry way when something upsets us.

To prevent us from behaving angrily, when something upsets us, we need to make ourselves less angry in general. This means concentrating on thoughts that are not angry in nature and we can achieve this in a number of ways. One way is through the use of a cognitive technique called '**thought blocking**'. This is a technique where whenever you find yourself having an angry thought you block it out of your mind by halting it. You block the thought by not continuing with the thought. You can even imagine the thought **exploding** or, you can just say "**I am thinking that unwanted thought, stop it**". You will find your anger levels decrease, with time, making you less angry towards others, so, allowing you to become a more efficient self-advocate.

Make time to **relax regularly** and ensure that you get enough sleep. Avoid **drugs** and **excess alcohol**. These lower inhibitions and we need inhibitions to stop us acting unacceptably when we're angry.

Advice on anger management and where you can seek help can be found at: www.counselling-directory.org.uk

Meditation.

The term meditation refers to a broad variety of methods and techniques aimed at promoting relaxation and building wellbeing and energy within you.

Meditation can also be used to overcome feelings of anger, fear, low confidence and procrastination. By meditating for twenty minutes a day, twice a day, morning and night you can overcome these negative emotions which hinder the self-advocate in you. It is a technique that involves focusing on your breathing, with your eyes closed, in a seated position and where you do not engage with any of your thoughts and just let them flow. Whenever you find your mind wandering, you return your concentration to your breathing and, as you get better and more familiar with the process, you can increase the amount of time spent meditating in increments of 5 minutes. The technique teaches you to live in the present and not spend your time focussing on the past (where all your fears stem from) and future

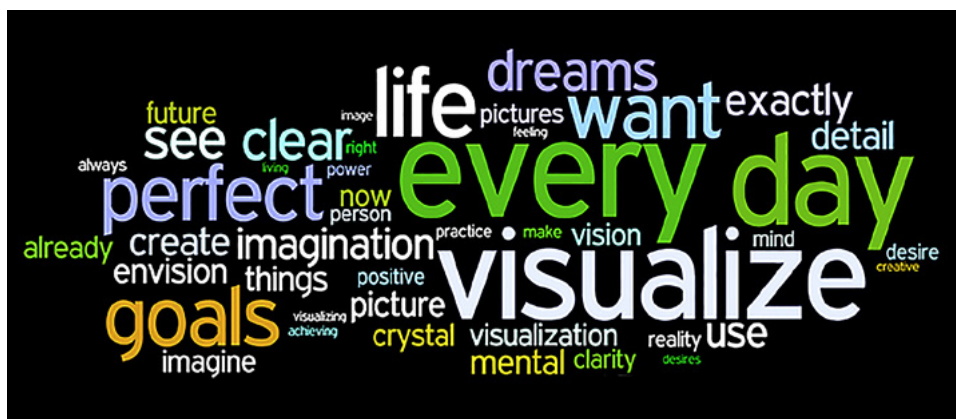


(where all events you fear will happen, if they happen) thus allowing you to live in a fearless present. The same technique can be used for other emotions such as depression and anxiety.

Meditation requires commitment and patience. Issues that go back to childhood can take months to address however, more recent issues can be lifted in a matter of days. Many mental health professionals advocate the use of meditation and mindfulness, for overcoming emotional distress/mental health conditions, over conventional medical drug treatments.

Information on meditation for beginners can be found at: www.wikihow.com/Meditate-for-Beginner and www.mindfulnessmeditationinstitute.org

Visualisations.



Visualisation can also be used to boost confidence and self-belief. Simply close your eyes and imagine yourself at the meeting, seeing it in your mind's eye, as though it is really happening. Imagine feelings of confidence. Imagine being told the things you want to be told. Hear and feel yourself talking confidently. Imagine yourself coming out of the meeting, thinking to yourself that the meeting has gone really well. All this can boost confidence and performance when it comes to attending the meeting in reality. This is because the mind can't always tell the difference between reality and fantasy and so, when you go into the meeting for real, your mind believes that it has done this before and it really went well. Your confidence will be increased and your performance will be heightened – attributes of an effective self-advocate.

Positive self-talk.



Positive self-talk can be used to bring out the self-advocate in you. Too often it is the things we tell ourselves internally (our thoughts) that hinder our ability to achieve/win. Too often our self-talk is negative. It is this **negative self-talk** that belittles us, causes us to have a low self-opinion, has a negative impact on our confidence and hinders our ability to self-advocate. When trying to resolve a dispute/issue with an authority, we must avoid saying things to ourselves such as

- “They are professionals and I am an ordinary person”.

- “These are intelligent people who have been educated and trained and I have not”.
- “These people will walk all over me as they are knowledgeable and more articulate than I could ever be”.
- “These people have no respect for people like me”.
- “I’m not capable of changing these people’s minds even if they did listen to me”.

This type of self-talk, if said enough times, will shape the image we have of ourselves and the perception we believe others to have of us, also. This will damage confidence and minimise the effect of our efforts at resolving our issues and disputes. Our **positive self-talk** should be along the lines of the following:

- “I have all the facts and a strong argument therefore I am more than capable of resolving this issue through self-advocacy”.
- “I will make these people sit up and take me very seriously”.
- “Those who meet me will be impressed by me and my arguments and therefore I am very likely to be successful”.

If we made these positive statements then our confidence would be boosted as well as our own self-image. We would believe the perception others have of us would be better. This, for us, would be a self-confidence booster and a self-advocacy performance enhancer.

Cynicism is an attitude or state of mind characterised by a general distrust of others’ motives. It is created by **negative self-talk** such as:

- “All these people are the same”.
- “People are just interested in making a saving”.
- “People couldn’t care about my wellbeing”.
- “There’s not a single charitable person amongst them”.
- “They just want to do what is the most convenient thing for them”.

These attitudes will only hold back your efforts to self-advocate and greatly reduce the likelihood of achieving the desired outcome.

What people who wish to self-advocate should be saying to themselves is:

- “Not everyone is only interested in making a saving”.
- “There are genuinely good people who wish the best for their clients”.
- “There are many principled people here who positively pursue their roles in helping and will not do what is convenient but what is best”.

Such positive self-talk will restore your faith in people and give you much more hope in resolving your issue/dispute. This will inspire you to give self-advocacy your best efforts, enhanced by increased confidence and the elimination of despondency and cynicism.

Positive affirmations.



Positive affirmation is another cognitive technique that can be used to bring out the best self-advocate from within you. Positive Affirmations are positive statements where you tell yourself that you have achieved what you wish to achieve. If you want a new house and your name is Mike, you might say:

- **“My name is Mike, and I am being provided with a new home by my Housing Association”**

Positive affirmations are statements in the present tense where you tell yourself you are achieving the outcome or result that you wish to achieve. This convinces the mind that the outcome has already been accomplished, so boosting your confidence, your assertiveness, your optimism and eliminating cynicism thus increasing your ability to self-advocate.

- These positive affirmations have to be said to yourself very often in order for you to convince your subconscious mind into believing that your aim and objective are being achieved.
- You should have about six affirmations for a specific issue and say them to yourself whenever you have a quiet moment such as walking the dog, doing the shopping, getting up in the morning or before falling asleep at night.

Acute anxiety.



All these cognitive techniques enable you to get the most out of your self-advocacy skills without your efforts being hindered by the limitations of negative thought processes and low self-belief.

Sometimes, we can become anxious when we are in the process of advocating for ourselves at an important meeting. This might be due to something happening unexpectedly; for example suddenly realising that we have forgotten to bring an important letter with us. This unexpected situation, with the resultant loss of control of how we had planned to present our case, can result in **acute anxiety** and a serious decrease in our ability to self-advocate. If this were to happen you can try to overcome the anxiety by simply breathing through your nose. **Slow regular breathing through your**

nose switches off the part of the nervous system that makes you feel fearful and anxious; this can be done during the meeting or just before it when you are feeling the anxiety building up. Anxiety can affect our ability to concentrate, as well our memory – both of which are essential components of self-advocacy.

Emotional spill-over.

The life issues that aggrieve us, and for which we need to self-advocate, can cause emotions in us such as frustration, anger, anxiety and depression. Such emotions not only affect our ability to self-advocate but can also spill-over into other areas of our lives.

For example, a Housing Officer has not recognised your need for a move to a new home, in an area that you have requested because of an antisocial neighbour bullying you and encouraging other local residents do the same. This decision is causing you to suffer from anger and rage. **“It’s just not fair”**. If these emotions are allowed to grow within you, they will eventually exhibit as aggressive behaviour which could drive friends and family away from you. This only serves to increase your isolation, making the bullying difficult to cope with and making you a more aggressive, unreasonable client in the eyes of your Housing Officer. Housing staff will make negative judgements about you, further reducing your chances of getting moved. Your anger may increase, driving more people away from you and spilling over into your work and family life. This could, in turn, affect performance on the job, as well as relationships with your seniors, and result in demotion or loss of employment. This will lead to you taking it out on your family – the most available persons at which to direct your anger. It is therefore very important for you to be able to manage these ill-emotions so that they do not **‘snowball’** and cause even greater distress in all areas of your life.



The damage created by **ill-emotions** can spread into all other areas of your life.

- Ill-emotion can cause issues such as loss of libido and impotence, affecting sex life in marriage or partnered relationships
- Ill emotion can cause cardiovascular complaints such as high blood pressure that can lead to neurological complaints such as stroke.
- Long term stress and unhappiness are now being shown to put people at increased risk of conditions such as dementia or exacerbate existing conditions and heighten care needs.

It is for this reason that every self-advocate should be aware of the importance of containment as well as the consequences of not containing these ill-emotions. Ill-emotions have complex consequences; this section has given you strategies to employ to help you attempt to eliminate them and protect yourself from their damaging, wide reaching effects.

Advice on simple steps in emotional containment can be found at:

www.wikihow.com/Gain-Control-of-Your-Emotions.

5. Researching and Retrieving Information.



Often when we self-advocate, a major barrier is knowing what information is out there - how reliable it is and how to find it. This is the vital information you can use to strengthen your case as well as telling you what your entitlements are. Relevant and accurate information will determine how you present your case and what you hope to achieve.

There are many sources of information such as the internet, libraries, Citizens Advice Bureau, Charities, local authorities, Charity helplines, Welfare Rights Officers etc.

The internet, for most of us, has proved to be a most useful and available resource of knowledge. The saying 'knowledge is power' is very true and, too often this is the reason that many power imbalances arise. This is especially so in areas of healthcare where the 'professional' has had extensive training whilst the client has not. Health professionals, such as doctors, receive very detailed training and have an understanding that will vastly dwarf a client's knowledge. This will inhibit the client from wanting to disagree with advice or an opinion on a matter related to their health. A professional is likely to be more able than a lay person at sifting information from the internet and deciding what good data is and what is not. Professionals have the advantage of being more able to evaluate critically and dismiss the information that we find and bring to them. For this reason we have to ensure that our information comes from reputable sources.



Today, everybody knows that the Internet offers information and data from many sources worldwide. Yet, many people do not know how to search the Internet most effectively, and many do not know how to evaluate the information they retrieve; because so much information is available, users need skills to both find and evaluate that information. There are six simple steps to searching for and evaluating information on the Internet:

The 6 steps.

Step 1: Questioning - Before going on the Internet think of the questions you want to ask

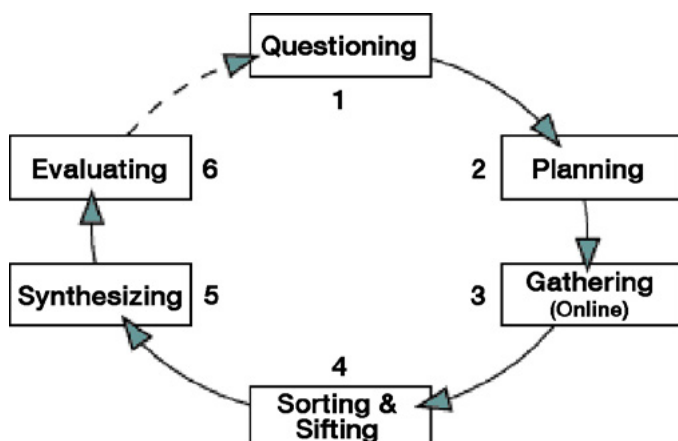
Step 2: Planning - Decide what words/terms you will use for your search and what search engine (Google) or website (see below) that you are going to visit

Step 3: Gathering - Gather all the information you need and "save it" to your computer

Step 4: Sorting & Sifting - Analyse all the information you have obtained

Step 5: Synthesizing - Draw conclusions from what you have found

Step 6: Evaluating - Assess the results and see how you can use them to support your case.



The following case studies are the result of scenarios discussed and developed at the workshops.

Case Study 1.

Mary came to Fairway Advocacy, having been referred by her charity, with the issue that her doctor would not recognise her as having the condition called Myalgic Encephalomyelitis (ME) also known as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue syndrome. In the past, this condition had been referred to dismissively as 'Yuppie Flu' as many health professionals did not recognise it as a physical condition but rather as a psychological condition which, like flu, would soon recover.

Mary made her advocate aware that for the last four years she had been suffering from what she was sure was CFS and that she had no energy to do anything. Mary said that this fatigue had taken over her life. She told her Advocate that, when she first went to see her Doctor, he did not recognise her symptoms as anything to be concerned about. Mary continued to tell her Doctors, over a four year period, that her symptoms were crippling her life. Each time she was told that she had nothing wrong with her; it was all in the mind, she did not have CFS and that she should just go home. The Doctors were becoming increasingly impatient with her each time she attended.

The Advocate helped Mary find information on CFS by suggesting she search the internet to find out about symptoms and how it is diagnosed. Mary eventually found this information on the internet at the National Institute for Care & Excellence (NICE) website. After Googling 'CFS Diagnostic Criteria', the first search result that came up was: '**Chronic Fatigue Syndrome-Diagnosis- NHS Choices**' (www.nhs.uk/Conditions/Chronic-fatigue-syndrome). After clicking on this link, another link to the National Institute for Care and Excellence – '**Guidelines on CFS**' appeared (www.guidelines.co.uk/nice/me). This provided a link to a paper on the '**Diagnosis & Management of CFS**'. Once this was clicked, all the tests and criteria for diagnosing CFS, as well as the appropriate management of symptoms, were found. With all the information gathered on diagnosis and management, Mary arranged a further appointment with her GP. With him, she went over her symptoms, how they met the criteria for CFS to be likely as well as the tests and management recommended to help her.

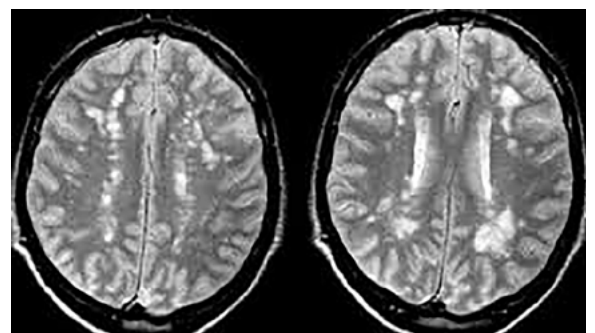
By asking the right questions, and using the information obtained, Mary has been able to have herself heard and has achieved the outcome that she felt that she was entitled to.

The internet can be used for preparing yourself for a meeting with a professional, in any of the public services, where you are making a case for obtaining a service/facility, that you feel should be provided to you, but has not been offered despite your previous efforts and attempts.

This is illustrated by the next case study.

Case Study 2

Linda has Multiple Sclerosis (MS) and believed that she was being victimised by her neighbours living in the flat above her. She felt that they were deliberately carrying out domestic tasks such as hoovering at all hours, arguing and playing the television or music loudly into the night. Linda was aware that her home was poorly sound insulated. When she raised these issues with the neighbours she received threats and abuse and, as a result, had discussed matters with the Housing Officer. Matters escalated when one of her neighbours' relatives threatened her in the local shopping centre and her husband's car was vandalised. Linda reported this to the police but they had taken no action saying that because Linda's complaints were due to the poor sound insulation of her property, they were powerless to intervene other than to investigate the alleged vandalism. Linda felt no one was taking her complaints seriously and she was being treated as a serial complainer. She felt that the fact that she had MS was being ignored completely.



Linda was becoming stressed, depressed and anxious. She had feelings of hopelessness, helplessness and despair and

developed a panic disorder. Her Advocate advised her to write a letter to the police informing them of their duty to protect her from further bullying, harassment and intimidation. Linda's Advocate also wrote a supporting letter to the police, sending a copy to Linda for approval, and a correspondence copy to her Housing Officer asking for a meeting.

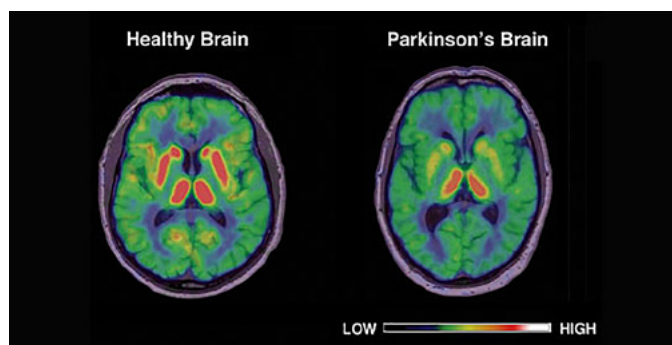
Linda knew that this stress was making the symptoms of her MS worse and decided to investigate this on the internet by going to 'google' (<http://www.google.com>). She simply asked the question **'can stress make my MS worse?'** This led her to the MS Society website (www.mssociety.org.uk/.../mental-health/stress-and-anxiety). Here she found a lead to an article showing that stress could lead to MS 'flare ups' and printed this off. She also found very useful advice on stress management (www.ms.about.co). Linda gathered up all this information and printed off the key article **'Stress may trigger MS flare ups in Women'** noting that this had been published in a medical journal, giving it added credibility. Linda sent these documents, along with her letter, to both the Police and the Housing Officer.

Linda was next invited down to the local police station for a meeting which she attended with her husband and advocate. She was told that there would be increased police awareness around her home and that the Housing Officer would be informed of the meeting and the action they were taking. Linda's Housing Officer was next in contact, arranging a meeting at which the relationship between mental health and worsening of MS symptoms and stress/anxiety were discussed. A week later, Linda and her husband heard that they were going to be rehoused in another part of Glasgow.

By asking the right question on the internet Linda had found answers that supported her case. She had gathered up the information, studied and selected and presented this to those in authorities and obtained the outcome she had wished.

Case Study 3

Tom had drug-induced Parkinson's disease and a care plan that had not been updated for over two years. His needs had increased greatly in that time, as a consequence of progression of his illness, and were not being met by his outdated care package. Tom had phoned the local social work department on several occasions but no one got back to him. He also tried unsuccessfully to arrange an appointment. He felt that he was being ignored and that assessment of his needs was long overdue. Tom was informed by his advocate that social work, like all professions, is accountable to its own professional regulatory body and would have a written 'professional code of conduct'. The Advocate suggested that Tom should access this code from the regulatory body's website and identify areas where he felt that his social work office had been in breach by ignoring his needs.



Tom put into the Google search box: **'Social Work Regulatory Body Scotland'**. This led to (www.regulatorylaw.co.uk/List_of_regulatory_bodies). Tom then clicked on the result which was: **'Scottish Social Services Council Home'** that led him to the link: **'SSSC Codes of Practice'** (www.sssc.uk.com/cody/documents/cody-kcard.pdf). This then allowed Tom to download a copy of the codes of conduct.

Tom next identified where he felt his social work department were not carrying out their duties and whether this amounted to a breach of code of conduct. He highlighted where he felt he had been let down.

"As a social service worker, you must strive to establish and maintain the trust and confidence of service users and carers" - He had no confidence due to the overdue assessment and what he saw as a lack of care.

"Being reliable and dependable Honouring work commitments, agreements and arrangements and, when it is not possible to do so, explaining why to service users and carers" - He felt they had been unreliable and had not honoured their work commitment by failing to respond to phone calls

Tom next wanted to find out how regularly a personalisation care package should be re-assessed by social work. He began by putting: **'Personalisation'** into Google which then led to him to **'Personalisation Care & Support plan'** (<http://www.nhs.uk/Conditions/social-care-and-support-guide>). After reading this, he learned that social work

are obliged to review his care plan at least once a year; for them to have gone more than two years without an assessment was a breach of guidelines.

With this information Tom wrote a letter to his social work office asking for a reassessment of his needs on an annual basis. He sent a correspondence copy to the Scottish Social Services Council enclosing copies of the information that he had obtained from the internet. Social Work responded immediately by inviting Tom to attend the local social work office where he was provided with an apology and was allocated a named social worker, with a date and time for reassessment. Tom was reassessed and now has a care plan that meets his needs.

By asking the right questions on the internet and using the answers to promote his case Tom has achieved the goals that he set out to accomplish. Social work has apologised for their failure to support him, he now has annual assessments of his progressive condition and a care package that gives him confidence that he can achieve the quality of life that he wishes.

Tom's approach, in getting the package to which he was entitled from social work, can be applied to any service provided by a professional body where you believe yourself to be entitled to better. If a doctor was constantly not recognising your needs you could look up the codes of practice from the General Medical Council (www.gmc-uk.org/about/council/register_code_of_conduct). If it were a lawyer you could access their codes of practice from the Scottish Law Society (www.lawscot.org.uk) and if it were a teacher you could access their codes of practice from the Education Institute of Scotland (www.eis.org.uk)

These case studies emphasise the strength that persons with disability have when they harness the power of the internet. Accessing the information available should help level the playing field between professional and client. Whilst most professionals do their best, within the limitations and resources available to them, not all do so and injustice results. The internet provides the client with power to challenge orthodoxy and this should be welcomed by all.

Useful websites.

There are many websites that you can access to obtain information that will help argue your case and allow you to learn about things that you are entitled to. This is a list of websites that might be of great use to you in presenting your case and making you aware of your rights and entitlements so that you are never denied support you deserve. This list is not exhaustive and there are many more that you can add as a result of your own searching.

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EMPLOYMENT & BENEFITS: DEPARTMENT OF WORK AND PENSIONS

<https://www.gov.uk/government/organisations/departments-for-work-pensions>

EQUALITY & HUMAN RIGHTS COMMISSION

<http://www.equalityhumanrights.com/>

JOB CENTRE PLUS

<https://www.gov.uk/contact-jobcentre-plus>

EMPLOYMENT TRIBUNALS

<https://www.gov.uk/employment-tribunals/if-you-lose-your-case>

LEGAL AID

<http://www.slac.org.uk/>

SCOTTISH PUBLIC OMBUDSMAN

<http://www.spso.org.uk/>

HEALTH:

NATIONAL INSTITUTE FOR CARE & EXCELLENCE

<http://www.nice.org.uk/guidance>

NHS HOMEPAGE (INFO ON CONDITIONS/TREATMENTS/SERVICES)

<http://www.nhs.uk/Pages/HomePage.aspx>

GENERAL MEDICAL COUNCIL

<http://www.gmc-uk.org/>

SCOTTISH PUBLIC OMBUDSMAN

<http://www.spso.org.uk/>

MENTAL WELFARE COMMISSION

<http://www.mwcscot.org.uk>

SOCIAL CARE:

SCOTTISH SOCIAL SERVICES COUNCIL

<http://www.sssc.uk.com/>

LOCAL AUTHORITY WEBSITES

<http://www.google.com> (put name of local authority into search box)

SCOTTISH CARE INSPECTORATE

<http://www.scswis.com/>

SCOTTISH PUBLIC OMBUDSMAN

<http://www.spso.org.uk/>

MENTAL WELFARE COMMISSION

<http://www.mwcscot.org.uk>

HOUSING:

HOUSING ASSOCIATION WEBSITE

<http://www.google.com> (Put name of housing association into google)

SCOTTISH HOUSING REGULATOR

<https://www.scottishhousingregulator.gov.uk/>

LOCAL AUTHORITY WEBSITE (put name of local authority into search box)

<http://www.google.com>

SHELTER SCOTLAND

<http://scotland.shelter.org.uk/>

SCOTTISH PUBLIC OMBUDSMAN

<http://www.spso.org.uk/>

CARE & REPAIR

<http://www.careandrepairsotland.co.uk/>

EDUCATION:

Equality & Human Rights Commission

<http://www.equalityhumanrights.com/>

SCOTTISH GENERAL TEACHING COUNCIL

<http://www.gtcs.org.uk/about-gtcs/about-gtcs.aspx>

THE BIG PLUS (Literacy Training)

<http://www.thebigplus.com/homepage>

GUARDIANSHIP

OFFICE OF THE PUBLIC GUARDIAN (SCOTLAND)

<http://www.publicguardian-scotland.gov.uk/>

MENTAL WELFARE COMMISSION

<http://www.mwscot.org.uk>

Not everyone has the skills to use, or access to, a computer and the internet. Most however have a mobile phone with internet access and can use this or alternatively ask family, friends or a care/support worker for help. Printing off relevant material can also be problematic with the cost of a printer and paper. The mobile phone can be used to download important papers/legislation that can then be forwarded by email. There are other non- internet based sources of information such as the Citizens Advice Bureau. You could ask them to help you locate information or direct you to sources of information that would strengthen your case at meetings.

Key Points:

- The internet empowers
- Don't be afraid of it. It's your friend and ally
- Make sure that the 'key question' you ask is relevant
- Print off the 'best information' to support your case
- Use this information at meetings with those who make the decisions that affect you

6. Communication.



Communication is simply the act of transferring information from one place or person to another. It is a key skill in self-advocacy. Communication is not just affected by confidence and assertiveness, as already discussed, but by how skilled we are at carrying out this activity. Many of us are skilled communicators and find that when writing a letter, choosing the right words to express ourselves appropriately as well as putting together a coherent case, the skill comes naturally. Others can struggle with this task and it does not come so naturally. Communication disorders are common in long term neurological conditions and fall into two groups:

- 1) **Hearing Disorders** ranging from hearing speech faintly to profound deafness.
- 2) **Speech and Language Disorders** that affect the way people talk and understand language (such as after a stroke).

People with Asperger syndrome can find it hard to read the signals and have difficulty in communicating and interacting with others. Asperger's is a form of autism, with a wide spectrum, affecting approximately 1 in 70 persons. The presence of this condition, often undiagnosed, presents a major obstacle to the ability to self-advocate. Asperger's is sometimes a problem in those with epilepsy.

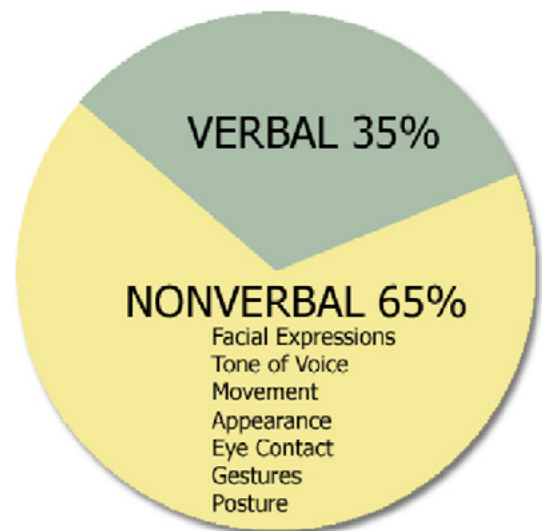
The essential skills in communicating are: listening, nonverbal communication, clarity and being concise (to the point), friendliness, confidence, empathy (understanding the problems of others), open-mindedness and respect. There are many ways in communicating and they are: **nonverbal (body language), verbal, letter writing, listening and reading**

Nonverbal Communication.

Although verbal communication is a primary means of expression, nonverbal actions such as body language, can greatly affect the way a message is perceived. An important point to remember is that only **35%** of the meaning of what we say and how it is interpreted by others comes from the words that we use. **The remaining 65% is determined by our body language**, facial expressions and tone of voice.

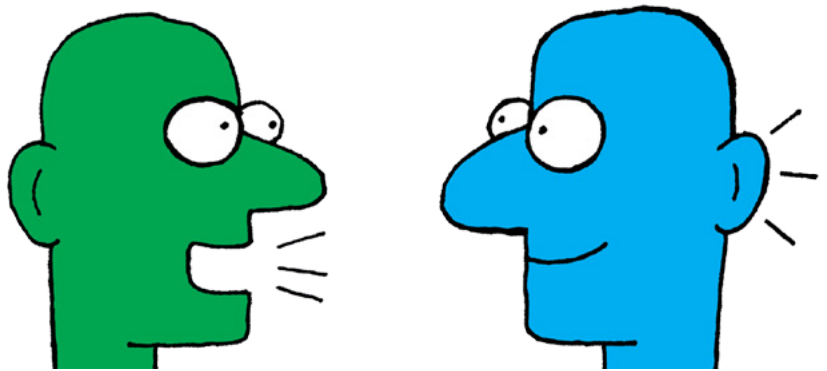
Your body language, eye contact, hand gestures, and tone of speech all influence the message you are trying to put across. A relaxed stance with arms open, legs relaxed and a friendly tone will make you appear approachable and will encourage others to speak openly with you. Eye contact is critical; looking the person you are speaking to in the eye demonstrates that you are focused on that person and their conversation. Avoiding eye contact and slouching in your seat will make you look shifty and deceitful. Also pay attention to other people's nonverbal signals while you are talking. From this you may get the feeling that they are not being straightforward with you or are conveying a decision, made by their superior, that they are not wholly comfortable with.

An example of how body language changes the meaning of a simple statement is in saying to someone that they are '**a terrible man**'. Just think of how many contexts and tones of voice accompanied by different types of body language can be applied to such a short statement. The result could range from being playful to being accusatory. How this simple statement is interpreted depends upon the emphasis on the words and the accompanying body language. This is important to remember when you present yourself and speak at meetings.



Verbal communication.

This involves the use of sounds and language to relay a message. Verbal communication serves as a vehicle for expressing desires, ideas and concepts and is vital to the processes of learning and teaching. In combination with nonverbal forms of communication, verbal communication acts as the primary tool for expression between two or more people. Misunderstandings can arise because of poor word choice, faulty communication techniques, and the use of unacceptable language.



When we wish to communicate our wants, needs and desires to others, through conversation, we can become emotional, especially if our frustrations cause us distress. If we become over emotional, we can come across as being angry, confrontational and so distressed that this becomes a distraction from our ability to communicate our needs to others. Such emotions can jeopardise the effectiveness of verbal communication especially if emotions appear confrontational and angry. Here people in authority will become judgemental and defensive towards us. This may result in decisions being made that are unfavourable to us. It is for this reason that we cannot allow ourselves to become emotional in meetings or in correspondence that might affect our future

When we are at a meeting discussing an issue that has a huge effect on our lives, it can be very difficult knowing just where to start. Sometimes the area of our life affected is so huge that there are multiple problems to discuss and there is so much to say and cover in the short space of time available. You may forget to say things or, alternatively mention everything at once and not give the specific detail which lets the listener appreciate the true impact that an issue has on your life. Trying to say too much will give your listener **'information overload'**.

It is also possible for you to have a **mental block**, not knowing where to start and failing to share with the listener the issues that you want to air. People can also, depending on the nature of their medical condition, have memory problems that will impede their ability to recollect and communicate vital information when being interviewed or making a contribution to a discussion. This may apply, for example, to persons with Stroke and Multiple Sclerosis.

For these reasons, you should write down, in advance, all the things you wish to raise at meetings in the order in which you wish to say them - and rehearse if necessary. This way, everything you wish to say is memorised and well-structured and nothing is missed out.

You should also try and think about and write down what questions you may be asked and have the answers prepared. Remember **'Research and Retrieval'** – using information from the internet to prepare yourself.

Success at meetings and interviews is less likely if you go off on tangents (no longer speaking about the issue in hand). You may be an extroverted person, or a nervous individual, and end up talking about a completely different issue with the original problem slipping out of the discussion. It is best to focus on one issue at a time and only move on to the next when you feel that you have made your case with the one in hand.

Websites such as www.skillsyouneed.com/ips/verbal-communication provide useful advice on developing communication skills.

Key points.

- Stick to the subject and avoid going off on tangents
- Be concise and brief
- Prepare what you are going to say
- Practice the answers to questions you might be asked
- Be aware of your body language

Letter and Email writing:

To arrange a meeting, to ask for something to be provided or to simply request more information from a professional person or body will normally require a letter or email. Occasionally, a telephone call is an option but rarely is 'dropping-in' on the professional advisable. They are busy and will not necessarily have your details to hand. It is for this reason that we need to rely on our literacy skills i.e. skills behind reading and writing. Around 1 in 4 Scots of working age will find themselves struggling with literacy skills during their working lives. Such persons can find advice and support at:

www.literacytrust.org.uk www.educationscotland.gov.uk



In writing letters or composing emails many of the principles of verbal communication apply. When we write we must:

- Make sure that our letter is correctly addressed to the appropriate person.
- Quote the correct reference details from previous communications to you.
- Ensure that the content is accurate.
- Ensure that the content is relevant and gets straight to the point, providing all the details required to communicate the message but nothing more.
- Keep it short – the reader may deal with loads of correspondence each day.

Firstly make sure that you are writing to the correct person – the one who is most closely involved in your case. Do not write initial correspondence to their manager or 'boss'. Give people the respect that their position deserves as this usually results in respect being given back. Going 'up the chain' to the 'boss', with early correspondence, only causes ill feeling. Make sure that you address your letter to the correct address (use earlier official correspondence to check this and your own personal reference details). **A common reason for not getting a reply is an incorrectly addressed letter.**

Make sure that the details in your letter are as accurate as you can make them. If you can't remember the date of an earlier meeting or the name of someone you spoke to, say so. Do not include information that you are unsure of and **never exaggerate** your case or make accusations

If your letter is too long then that means there is a lot of irrelevant information in it and is probably full of what is called 'waffle'. Waffle means repetitive and irrelevant content. If the letter has too much irrelevant content in it, your message will be lost amongst the irrelevant content. There is a danger that the reader might remember the irrelevant and miss the relevant information. This is especially the case if the reader finds the irrelevant information more interesting than the relevant information! If the letter is too long the reader might not finish it due to time constraints and decide to read the rest later on but forgets to do so. Busy people get impatient reading a long letter and will stop reading it if they can't immediately see the point you are trying to make.

Before writing a letter or sending someone an e-mail it is important to have thought through what you want to communicate in the content in your message and how you will communicate it i.e. the tone of the letter. The kind of response we get is very dependent on how our letter reads. Sometimes we want our letter to state dissatisfaction at something and how we wish this to be remedied. We want our letter to state this in an assertive but not an aggressive tone. If the letter is aggressive, it may not get any response at all or, it will get a response that will be defensive and uncooperative which creates an 'us and them' stand-off that compromises the achievement of your desired resolution.

You must avoid:

- Making accusations, blaming, being over critical
- Using bad language, name calling, using strong words to describe the reader's actions or incentives e.g. 'neglect', 'hate', 'unprofessional'
- Being cynical or making 'veiled' threats

When you are writing a letter to an authority such as social work, and earlier letters have gone unanswered, it is worth sending a **copy** of your next letter to a **third party** (a person or group besides the two primarily involved in a situation or dispute). This lets the third party know that you have been trying to contact that person and have

made no progress. The third party is usually an individual that the person, to whom you sent your original letter, is subordinate (for example line manager or team leader). The copy could also be sent to the relevant professional body (for example Social Work Council) or, if they know of your case, your MSP or Local Councillor. Sending copy correspondences, when necessary, makes you more likely to get a response and achieving your desired outcome. We call this copy of the original letter, that we send to a third party, a **‘Correspondence copy’ (CC)**. You inform the main recipient of your letter that a correspondence copy has been sent to a third party by putting at the bottom of your letter as : **CC: Name of Person/Organisation/Department, Address, Postcode**

An example of a case where someone has sent a correspondence copy letter, as well as used research and retrieval skills, is as follows:

Case Study 4.

David has epilepsy with his seizures occurring upon awakening. David’s neighbour was playing music at all hours, especially in the middle of the night, and was bringing friends home late. David was being woken by his neighbour’s activities and as a result having seizures in the middle of the night. The seizures left David confused and drowsy. He could never phone the Environmental Protection Services people as by the time he had recovered from his attacks the noise had finished. He told the Environmental Control Officer but they could not provide him with a noise meter. David had also complained to his Housing Association but they kept telling him that this was an issue for the “noise pollution team”. By now his neighbour was complaining to David about his ‘unreasonable demands’ and becoming hostile. David wrote to his Housing Association saying that this was unfair and that, as a tenant, he expected the Housing Association to resolve this issue.

David researched on the internet who the people above his Housing Association were and found them to be the **Scottish Housing Regulator** (www.scottishhousingregulator.gov.uk). David next researched what his tenancy rights were on the Housing Association’s website and printed off information on the right to expect the Housing Association to maintain a safe and friendly environment in which he could live. David also printed off, from the Scottish Housing Regulator website, the ‘Scottish Housing Charter’ (www.housingcharter.scotland.gov.uk) that sets out the expectations that a Housing Association have a duty of responsibility to meet. David sent a letter, along with the material that he had printed off, to his Housing Association with a correspondence copy letter to the Scottish Housing Regulator. After the Housing Association received this correspondence, the noise team installed a noise monitor in his home. David’s neighbour was recorded playing his music loudly and was fined; David could now go back to living a peaceful life in his home.

By researching his case and sending copy correspondence to the relevant supervising body David achieved the outcome that he had been aiming for and felt that he had been fairly treated.

Finally and most importantly it is vital when writing in response to a letter from a party that has upset you that you allow yourself to **calm down and think about what your next best move forward is**. It is important that you do not write a **‘knee jerk response’** as it will be full of emotion, causing you to say things that are not in your best interests and which you will subsequently regret. A knee jerk response should always be avoided as this is fuelled by emotion and not by logic and good problem solving. To avoid this, if a letter has annoyed you, don’t reply until the following day – ‘sleep on it’ and then make a measured response. Never reply to correspondence, by email or letter, late at night as this is often when we feel at our boldest and in the morning, we will regret it.

Key Points.

- Make sure your letter is accurate
- Avoid a confrontational tone
- Focus your letter on a specific issue
- Copy correspondence to relevant bodies
- Pause and think before you reply to correspondence that upsets you

Listening:

“If we were supposed to talk more than we listen, we would have two tongues and one ear.” Mark Twain
-American Writer.

Listening involves making the effort to hear something or to pay attention. When we hear something that we don't like we often 'turn off. Advice on good listening to obtain information, to understand and to learn is available at <https://www.mindtool>

Verbal communication is two ways communication. It involves both speaking and listening. **Listening is a skill in itself as it requires concentration, processing and memory.** When we communicate most of our time is taken up through listening.

In order for us to communicate effectively by listening, we need to take in what is being said (**comprehension/concentration**), make sense of it (**interpretation/processing**) and remember it (**memory**). Any of these can be affected by mental health problems such as depression, anxiety and stress. This is additionally true when you have a neurological condition that also affects **cognition**. All these components explain the listening difficulties that can arise in neurological conditions such as Multiple Sclerosis, Stroke, and Head Injury etc. The additional side effects of powerful medications to treat these conditions also affect the ability to listen. In general, approximately 1 in 12 or 8% of our population have some degree of hearing impairment with 30% over 65 and 50% over 70yrs.

If you have a hearing impairment you should declare this in advance of any meeting so that the necessary steps can be taken to assist you.

If any of these components are damaged we cannot make sense of or retain any information that is being verbally communicated to us. That way, we can leave a meeting none the wiser: We cannot take in any new information nor can we remember anything that is told to us. This hinders any ability we have to progress and improve things for ourselves through communicating with other persons. This will affect our ability to self-advocate.

These mental health and neurological effects can be reduced by using techniques that help us focus on listening and retaining important information: **Reading, cardiovascular exercise** e.g. cycling, swimming, running, **thought blocking, meditation, learning something new** e.g. a new language, taking up a hobby that requires you to stay focussed such as debating, card tricks and many more. All these techniques induce a process known as **neurogenesis** which has claimed to allow the brain to grow more grey matter, thus improving concentration, processing and memory, making you a better listener and more creative problem solver - key elements of self-advocacy. It has been suggested that these techniques may help prevent or slow dementia (Alzheimer's disease).

If you struggle to follow things that someone is saying to then you could **take notes** as a record of your meeting. Note taking also aids maintaining concentration and makes you aware of when your understanding of what is being said comes to an end. This will enable you to ask someone to repeat themselves or to speak to you in layman terms. The notes also make you retain, in your memory, everything that has been said by reading them over and over to yourself.

When attending a meeting being an attentive listener is important to your cause and ability to self-advocate. Listening is as crucial as speaking. Many people get into the habit of believing that the more they say the more likely they are of getting an outcome. This is not the case. By not listening you can prevent yourself from learning what your rights and entitlements are and what problem solving steps you need to take to access these. People can become very impatient with someone who always speaks but never listens. It can cause people to fall out and lose patience with each other. This is why judging how much speaking and listening you should do is as much a social as it is a communication skill.

Key Points

- Don't Interrupt the speaker
- Sit still fidgeting makes you look bored.
- Be attentive to non-verbal cues: Pay attention to what the speaker doesn't say
Look for non-verbal cues such as facial expressions and posture to get the full gist of what information the speaker is conveying.
- Lean toward the speaker: You will appear to be more engaged.
- Repeat instructions and ask appropriate questions:
- Do not be frightened to ask for clarification especially where professional jargon is being used.

Reading



This skill can be equally affected by impairment in concentration, processing and memory brought on by neurological and/or mental health issues. This impairment can be in part remedied by practising your reading skills simply by reading newspapers, books and any other reading material as well as employing techniques like meditation.

Occasionally “official” letters use the technical language and jargon of the professionals who have written them. Don't be afraid to challenge correspondence that you don't understand or to approach a friend or family member to help you ‘translate’.

If you struggle with reading as a consequence of poor reading skills (1 in 4 people) brought on by little education or learning disability then you can access reading skill classes by searching the big plus website (www.thebigplus.com)

7. The Law.

It is helpful for the Self-Advocate to know a bit about the law. Many cases revolve around the laws or Acts. When you feel you are the victim of an injustice or are unhappy at the way in which a professional is handling your case, it is wise for you to know the relevant legislation. This is more so where you believe that your human rights are being compromised, through a decision made by an authority; you see this decision as having a detrimental effect on your life. A good example of where some knowledge of the law is useful is **Guardianship**. Here someone else is granted powers to make decisions over your financial as well as wellbeing interests.



It is not expected that any Self-Advocate should know the Law as well as Lawyers but when self-advocating, it helps to know where you can go to find out what the law says about your rights and entitlements are. Sometimes, legal advice from a Lawyer is essential but one aim of successful advocacy is avoiding the unnecessary costs and stresses of going to court.

Acts of the Scottish Parliament are available at www.legislation.gov.uk and www.scottishlaw.org.uk/scotlaw/statute.

For example if you go to (www.legislation.gov.uk) and look up Disabled Persons' Parking Badges (Scotland) Act 2014 you will find 'contents', 'explanatory notes' and additional notes to help you understand the legislation and how it is enforced. You do not need to read the Act in full as the summary of the Act will usually give you the level of information that you require.

This Section of the guide will look over some essential legal Acts, relevant to advocating in relation to long term neurological (and physical) disability, and is illustrated by case studies where people have researched the law and kept themselves informed of their rights and entitlements ensuring that there is no power imbalance created by a lack of knowledge.

The Acts selected and the scenarios provided are the result of the interactive workshops carried out during the shaping of this guide. Hopefully each of the case studies below will help remind you of each Act and how they can be researched and used in your self-advocacy practice.

1) ADULTS WITH INCAPACITY ACT (SCOTLAND) ACT 2000



This law covers the rights/entitlements of those people with varying degrees of cognitive function. It is a law that protects those with impaired cognitive function from exploitation and other risks associated with the designating of decision making powers affecting a person's physical and mental wellbeing to a named individual/s

Case Study 5.

Derek lives in a residential home after having had a head injury and had nominated his mother as his Power of Attorney with power over his finances. Derek wanted to take this power away from his mother as he no longer trusted her. He felt that his mother was overpowering and the nursing home staff had found her aggressive to them, especially if they told her anything that she did not want to hear. Derek was told that to revoke the Power of Attorney he would have to put a document together that specified what powers he wanted revoked from his mother; this would be sent to the Office of the Public Guardian for consideration. Derek did this and was later informed by nursing home staff that his application had been unsuccessful and he would have to allow his mother to continue. Derek was convinced that he did have the capacity to terminate a Power of Attorney and researched this using the internet. He searched '**Power of Attorney Scotland**' which took him to the Office of the Public Guardian (www.publicguardian-scotland.gov.uk/power-of-attorney) that explained to him what a Power of Attorney was. He next went to www.legislation.gov.uk to learn more about the 'Adults with Incapacity Act 2000' and Power of Attorneys. He found a

short guide on the Scottish Government website. Derek studied the section on revocation (cancellation) of a Power of Attorney and highlighted that the act stated:

*“You (whilst you are capable) may revoke (cancel) the power of attorney (or any of the powers granted by it) after the document conferring the power of attorney has been registered, by giving notice in writing to the Public Guardian”
“The document must be signed by the granter and must incorporate a certificate in the prescribed form by a practising solicitor, a practising member of the Faculty of Advocates or a registered and licensed medical practitioner which certifies that he or she: has interviewed the granter immediately before the granter signed the document; is satisfied, either because of knowledge of the granter or because of consultation with another person (whom he or she names in the certificate) who has knowledge of the granter, that at the time the revocation is made the granter understands its effect; and has no reason to believe that the granter is acting under undue influence”.*

What Derek understood from this was that protocol had not been carried out correctly and that he should have been interviewed by a solicitor or a doctor to determine that he had capacity (understanding) to make such a decision as to revoke his mother’s Power of Attorney. After Derek discovered that the procedure for assessing his capacity to revoke his mother’s Power of Attorney had not been followed, the proper assessment was duly carried out. Derek was found to have capacity to revoke his Mother’s Power of Attorney and subsequently arranged for this to be transferred to a close friend that he could trust. Derek felt that the nursing home had been bullied by his Mother into not following procedure. As a result he searched ‘**Complaints against residential homes in Scotland**’ and he was taken to the Care Inspectorate’s website (<http://www.careinspectorate.com>) where he learned how to make a formal complaint about the care staff’s conduct with respect to his lack of a formal assessment of his capacity.

Derek had used the internet to find out that protocol had not been followed and that his initial assessment of his capacity to make his own decisions had been unlawful. He next complained to the appropriate body to ensure that what had happened to him was not repeated with someone else. He had effectively self-advocated.

2) MENTAL HEALTH (CARE & TREATMENT) (SCOTLAND) ACT 2003.

This is an act that addresses the treatment rights of an individual with a mental health disorder, learning disability or some other related condition e.g. dementia. This act determines when and how a person with a mental health disorder can be treated: When a person with a mental health disorder can be treated or taken into hospital against their will: What the rights and safeguards of these rights are of the person with a mental health disorder



It is an act that determines when emergency detentions, short term detentions and Compulsory Treatment Orders can be implemented and the procedures to be followed and the criteria to be met behind the designating of these detentions/orders. This act gives all those with mental health conditions a legal right to an independent advocate though sometime self-advocacy is necessary.

Case Study 6.

Peter had a major depressive disorder after losing his wife. He was very irritable as a consequence of his depression. He had been assaulted by a group of youths and was left badly injured and experiencing post-traumatic stress. The youths were arrested but were found not guilty. Peter found living with the loss of his wife, as well as the great injustice of seeing these youths walking free from court, emotionally overwhelming. He turned to alcohol, to help him cope, and became alcohol dependent. Peter’s depressive disorder, his alcohol addiction and the lack of closure from the assault caused his behaviour to become challenging. As a result, he frequently displayed antisocial behaviour in front of neighbours and members of the public.

The Police were frequently picking him up and called his Social Worker. She believed Peter needed some type of treatment though, to date, he had been refusing all help and support offered by his General Practitioner. Peter was informed by his Social Worker that they would be applying for a Compulsory Treatment Order which would mean that a mental health tribunal would decide if Peter would be obliged to undergo treatment. Peter had very little faith and trust in authority and the establishment, as a consequence of bad experiences during adolescence and

the recent court case outcome. Because of this, he decided to research the process behind Compulsory Treatment Orders, in terms of their creation and implementation.

Peter went to the internet and entered the keywords '**Compulsory Treatment Order**'. He was taken to a search result entitled '**A Guide to Compulsory Treatment Orders** (www.mwscot.org.uk). This Mental Welfare Commission Scotland website explained the relevant part of the Mental Health (Care & Treatment) (Scotland) Act 2003. From this he understood the process offered to help him. He was confident that protocol was being followed and that everything that was being done was in his best interests.

Peter had been suspicious of authority because he felt he had been let down. By searching for information he had become his own advocate and now realised that his Social Worker had followed protocol and had his best interest at heart. This restored his faith in the 'system' and made him appreciate how much people were trying to help him.

3) ADULT SUPPORT & PROTECTION ACT (SCOTLAND) ACT 2008.

This act is about protecting adults at risk from harm. The Act supports and protects such adults by: Placing an obligation on local authorities to make enquiries and investigations when required to determine if any action is required for the purpose of preventing or bringing to an end any harm happening: Placing an obligation on specific organisations to work alongside local authorities as well as with each other over investigations with regards to adult protection: Introducing a range of protection orders that include assessment orders, removal orders and banning orders: Provide a legislative framework that can be used for the creation of Adult Protection Committees made up of local multi-agencies across Scotland.



The Act defines someone as an Adult at risk of harm who satisfies all four criteria:

1. Over 16 years of age.
2. May not be able to protect their wellbeing, interests, property and rights.
3. At risk of being harmed by others.
4. Have a disability/illness/mental health condition that puts them more at risk of being harmed than anyone who is not affected by such a disadvantage.

Case Study 7.

Gill has Multiple Sclerosis (MS) and came from a financially well-off family. She lived in her own home and had separated from her husband as a consequence of domestic abuse. Gill believed that her husband was only interested in her wealth and that he had been very unsupportive following her diagnosis of MS some years earlier. In more recent times Gill had been physically attacked by her husband on a number of occasions. Now, he could not accept that Gill wanted a divorce and that their relationship had ended. Their home was in Gill's name. Despite Gill ordering him out of the house he kept re-appearing on her door step, wanting to be let back in. Gill resisted this but was fearful that she would be attacked and embarrassed that neighbours might hear the insults that he would fling at her. She had reported previous assaults to the police but she never charged her husband as she could not deal with the stress this would involve. She just wanted her husband to leave her alone to allow her to get on with the rest of her life in peace.

Gill thought that her husband was guilty of harassment and that there must be a law that banned him from coming anywhere close to her, if she did not wish this. Gill put the word '**banning**' into the search engine on her computer and came up with the term '**banning order**'. Gill selected this and her third search result was called '**Banning Orders-Legislation.gov.uk**'. Gill clicked on this and she was taken to the Adult Support & Protection (Scotland) Act 2007 page on the www.legislation.gov.uk website. Gill also found valuable information at www.actagainstharm.org/questions/banning-orders

She read that a Banning Order was granted by a Sheriff where "an adult at risk is being, or is likely to be, seriously harmed by another person and the Sheriff is satisfied that the banning of that person will protect the adult at risk's well-being or property". The subject of the ban (Gill's husband) could be banned from a specific area (Gill's home).

The Sheriff can also grant a **temporary banning order** pending the decision being made over a full banning order thus allowing time for mediation. Although a **breach of the order** is not a crime, actions resulting from it, such as breach of the peace or assault, are. Gill noted that if there are no criminal proceedings, she could raise a civil action against her husband for breach of the order and that he would then liable to be held in contempt of court, attracting a penalty or a **fine or even imprisonment**.

As a result of her enquiries Gill had learned that she could apply to the Sheriff court for a banning order. Gill approached her Local Council Social Work Dept. and received support and help with the application. She was successful and a banning order was granted by the Sheriff. A Power of Arrest was attached to this banning order so that if her husband came anywhere near her in person the police would have the power to arrest him without warrant.

4) THE PATIENT RIGHTS (SCOTLAND) ACT 2011

This Act aims to improve the experiences of those using health services and to encourage those receiving care to become more active participants in the health care that they are in receipt of. It places a duty on NHS Boards in Scotland to uphold 18 healthcare principles that cover:



The right to a health care service that should take into account their needs, determine as well as consider what would be in the best interests of the patient, promote the participation of patients in the making of decisions affecting both their physical and mental wellbeing and educate the patient with the knowledge and appropriate support for them to be able to make informed decisions regarding their care.

The right for patients to evaluate the health care that they receive through feedback and the raising of concerns/complaints. The Act places an obligation upon Health Boards to monitor and learn from feedback and complaints received.

A right of access to the independent Patient Advice and Support Services which helps people articulate their feedback/concerns/complaints and signposts to further support facilities such as advocacy services or communication support services. This body will also inform patient of their rights and responsibilities as a client of the health services

The Act provides a patient with a **Charter of Patient Rights and Responsibilities**. This can be downloaded by visiting the Scottish Government website after searching for Patient Rights (Scotland) Act 2011 and clicking on the result called “**Patients Right- the Scottish Government**” and then on “**Charter of Patient Rights & Responsibilities**” (www.gov.scot/Resource/0039/00390989.pdf)

Case Study 8.

John has Epilepsy and was on an anti-epilepsy drug that had reduced his seizures by 75%. John was pleased with this achievement but he was very concerned as his drug treatment carried significant side effects of which one was appetite stimulation. John constantly felt hungry and craved food. His weight had gone from 12 to 15 stone since starting this drug and he was continuing to gain weight. John felt vulnerable as he was becoming obese and knew of the risks of developing heart problems, stroke and diabetes if he did not, as his GP had advised, lose weight. Being overweight was also affecting his self-esteem.

John brought these concerns up with his Hospital Consultant saying that he wanted to switch to another drug. The Doctor told him that he had a choice of having poorly controlled epilepsy or being overweight and that if he were John he would prefer being overweight, any time. John was not happy with this but his Doctor refused to take him off his medication and use an alternative drug. John did not think this was right and was convinced that he surely must have some say in the matter. Wondering what his rights as a patient were, he searched ‘**Patient Rights**’ and came to ‘**Patients Right (Scotland) Act 2011**’, legislation that he did not know existed. By clicking on this he was taken to the Scottish Government’s Patient Rights Act page (www.legislation.gov.uk) where there was a link for him to click taking him to the ‘**Charter of Patient Rights & Responsibilities**’. (www.gov.scot/Publications/2012/04/6273)

From this John learnt the following:

“You have the right to be given the information you need to make informed choices about your health care and treatment options. You have the right to be told about the care and treatment options available to you. You have the right to be told what the care or treatment will involve, including the risks and benefits, and what may happen if you do not have the treatment.” (Page 9 Charter of Patient Rights & Responsibilities)

“You have the right to accept or refuse any treatment, examination, test or screening procedure that is offered to you. If you can understand the information you are given and are capable of making a decision for yourself about the care or treatment you are offered and appropriate available alternatives, then you have the right to accept or refuse any treatment, examination, test or screening procedure, or to take part in research.” (Page 11 Charter of Patient Rights & Responsibilities)”

John could see from this that he had the right to be given information about different treatment options and the side effects and risks of taking each. He felt his hospital doctor had failed him in this respect. John told his doctor that had he been informed beforehand, that weight gain was a risk of the medication prescribed, he would not have taken this drug in the first place and would have requested an alternative. In essence John felt he had been denied the right to make his own informed choice about his treatment.

John told his doctor that he was in breach of the Patient Rights Act and to comply with this he was obliged to follow John’s choice of withdrawing the drug he was on, making him aware of alternative choices and the risks of each so that John could make a balanced decision on what medication he now wished to use.

John’s medication was withdrawn and he was put on a new anti-epilepsy drug that did not stimulate his appetite. John went on a diet and with exercise he succeeded in losing the excess weight that his previous medication had caused. As a result his self-esteem improved and long term health worries settled. John was happy that he had made the right decision despite a slight increase in the frequency of his seizures.

John, through searching the internet, had come across legislation that he had not previously heard of. He was able to use this to self-advocate for his right to choice. From this experience he has been able to tell others about their patient rights.

5) SOCIAL CARE (SELF-DIRECTED SUPPORT) (SCOTLAND) ACT 2013.

This act provides clients of social care services with a range of choices about how their social care services are provided, thus empowering clients to make a decision on how much autonomy they have over the arrangement of the support services that they are in receipt of.



The Act offers clients 4 different formats through which support is provided:

- 1. Direct Payment: you get the funding and organise your own support**
- 2. You direct the support available to you: you choose your support but others (Local Authority) organise and manage financial arrangements**
- 3. The Local Authority directs the support**
- 4. A combination of 1-3**

Case Study 9.

Sharon has a spinal injury as well as a major depressive disorder and as a consequence requires a lot of community care. As a result of her severe depression, following her self-directed support (SDS) assessment, it was determined by her Social Work office to place her on option 3. This option involves the Social Work Department arranging all of her community care either from their staff or from the authority’s preferred provider. The reason for following option 3 was that Sharon’s depression caused lethargy, fatigue, memory issues, and poor organisation skills thus rendering her unable to arrange her care package and payment to her carers. At this time it was believed and agreed by all, including Sharon, that this was the best option.

Sharon attended a Cognitive Behavioural Therapist and received CBT. After 6 months of this treatment Sharon experienced huge improvements in her mental health and had more energy and was feeling more optimistic. She was no longer spending large periods of the day suffering from fatigue and lethargy or being asleep. She now felt that she could be given more responsibility with her SDS and perhaps be allowed to try option 1 allowing her to take control over arranging her own care and payment to her carers - effectively becoming their employer.

Unfortunately Social work did not share her optimism and refused to allow her option 1 (Direct Payment) nor would they allow her option 2 or 4. Social work insisted that Sharon remain on option 3 without carrying out an up-to-date assessment. Social work told Sharon that once she was allocated an SDS option it could not be changed. Sharon did not accept this as she knew that a person's health changes with time. She reasoned that while some people on SDS will have deteriorative conditions, meaning their options will have to change with time, others will improve and therefore there was surely scope for flexibility and the recognition of change in an individual's healthcare status.

Sharon looked up '**Self- Directed Support**' on the internet and found the **Social Care (Self-Directed Support) (Scotland) Act 2013** (www.gov.scot/.../Support/Self-Directed-Support). She also found the Scottish Government site (www.selfdirectedsupportscotland.org.uk) this being a one-stop-shop for information about Self-directed Support for service-users and health and social care professionals.

Sharon noted from Section 13: *"Further choice of options on material change of circumstances"* that *"if after the choice is made the authority becomes aware of a material change in the person's circumstances the authority must offer the person another opportunity to choose one of the options for self-directed support under the section concerned"*.

From section 13, subsection C, Sharon could see that Social Work have to reassess a person's suitability for all four options if there was ever a material change in her circumstances. It could not be denied that the improvement in her depression was significant enough to be considered a "material change in circumstances". Sharon got a written supporting statement from her therapist confirming her improvement.

After Sharon made Social Work aware of her knowledge of Section 13, Subsection C of the '**Social Care (SDS) (Scotland) Act 2013**' and had provided them with her therapist's statement, her case was reconsidered and she was designated option 2. Sharon and Social Work now work together in arranging Sharon's care with Sharon picking and choosing her care and Social Work making the arrangements and dealing with the finances.

By accessing the Act on the internet Sharon was able to study it and find that she was being denied the opportunity for reassessment of her option choice. She acted as a self-advocate to bring about change and ensure that her social work department understood that reassessment was something that they should have offered earlier.

6) DATA PROTECTION ACT 1998

This is the main piece of legislation that governs the protection of personal data in the UK. The Act's definition of "personal data" covers any data that can be used to identify a living individual. Anonymised data (data that does not identify you by name) is not regulated by the Act.

The Act gives a person a right to any records that have personal information about them. Under Data protection all a person has to do to access records and documents that contain personal information about them is put in what is called a 'Data Protection Request'. This puts a legal obligation on the organisation or authority that holds such information about you to share it with you.



A **Data Protection Request** is carried out by writing a letter to the organisation that holds information about you asking them to share this information with you. This is usually provided at no cost but some organisations can charge if the personal information requested is from certain sources such as health or education records. Most organisations will have a Data Protection Officer who will respond immediately to your request, giving you some idea of the

timescale involved in retrieving your information. They cannot disclose data to you that names a third party unless that person consents. The names of a third party can be 'blacked out' or **redacted**. The legal definition of **Redact** is removing text or images from an original document. When applying in writing for personal information, it is wise to find out the name of the organisation's Data Protection Officer and address correspondence directly to them. This will save time and ensure that you get an immediate response.

Case Study 10.

Michael was involved in a road traffic accident, five years previously, and believes himself to have had a head injury that was unrecognised at the time and thus untreated. He feels this has left him living with uncontrollable symptoms such as loss of inhibition e.g. shouting out loud, saying inappropriate things to people and behaving in other antisocial ways. This has resulted in Michael falling out with his neighbours. He was initially told by his neurologist that these symptoms were the result of having sustained a significant head injury at the time of the accident and Michael's lack of memory about the event would seem to support this. Unfortunately his psychiatrist over-ruled the neurologist's opinion and diagnosed Michael with Post Traumatic Stress Disorder (PTSD) without carrying out any of the neuropsychology tests that would have confirmed head injury or not. This resulted in years of dispute between Michael and his treating psychiatrist.

Michael told his G.P. that he did not wish to be seen by this psychiatrist again and wanted referral to one that he could trust and who would carry out the neuropsychology assessments that Michael believed necessary. His new psychiatrist insisted that Michael had already had these tests performed and that they supported the opinion that he had PTSD and had not had a head injury. When Michael asked to see the tests results he was told that they had not yet been filed in his medical records.

Michael, unconvinced by what he had been told, researched on the internet '**Right to Patient Information**' and found '**How to access your NHS Medical Records**'.

(www.nhsmedicalrecords.org.uk). From this he noted that to access these, including the results of tests, he should write a request to the Records Manager at the hospital he had been attending. Michael also found the Government site for the Data Protection Act 1998 (www.gov.uk/data-protection) and learned from this that when making a complaint, if confidential information had been lost by an organisation, you contacted the Information Office Commissioner (www.gov.uk/.../information-commissioner-s-office). Michael wrote to his psychiatrist saying that he would put in a request, under Data Protection Act, for a copy of the test results. He said that if they could not be found, but it was still claimed that they had been carried out, he would next make a complaint to the Information Office Commissioner asking that the mishandling of his confidential information be investigated.

Michael subsequently received his records and found that neuropsychological test had never been performed. He received an apology from his psychiatrist, was referred on to a different psychiatrist, has had neuropsychological testing and is awaiting the results of this.

Michael used Data Protection Act to expose a failure to have him properly investigated and the misconception by his psychiatrist that he had. Through self-advocacy the issue of whether he has had a head injury or suffers from post-traumatic stress disorder will at last be resolved and Michael will be able to accept either diagnosis and get on with his life.

7) ANTI SOCIAL BEHAVIOR (SCOTLAND) Act 2004

The Act give the legal definition of antisocial behaviour as: "A person engages in antisocial behaviour if they act in a manner that causes or is likely to cause alarm and distress or pursues a course of conduct which causes or is likely to cause alarm and distress to at least one person who is not of the same household". Antisocial behaviour includes the following: noise disturbances (loud music, shouting etc.), harassment, racial harassment, violence and threats of violence, verbal abuse, vandalism etc.



Case Study 11

Desmond had poorly controlled night time epileptic seizures and chronic back pain. Desmond's next door neighbours party into the night and in the summer would sit out in the garden, drinking and shouting into the small hours. To make matters worse the couple's children often played football in the garden late at night and Desmond's bedroom looked out over this garden. Desmond could not sleep in his bedroom nor could he sleep downstairs due to his back pain. He was therefore disturbed many times in the night by the noise that induced nocturnal (during sleep) epileptic seizures. Desmond was concerned that the sleep deprivation that he was chronically experiencing might result in day time seizures with loss of his driving licence and that this would cost him his job. He was becoming increasingly despondent about his situation. When he raised the issue with his neighbours he was verbally abused. He was scared to bring up the matter of his epilepsy as he believed that would lead to disability abuse.

Desmond went to the police but they said that it was not a crime to have a party nor was it a crime for kids to stay up late playing football. Desmond went to his Council but they said that because the couple's house, whose back garden bordered Desmond's, was in a different Local Authority area they could do nothing. Desmond went to the couple's Local Authority and they said that because he was a resident of another Local Authority area they could do nothing for him either. According to what he had been told by these authorities the situation appeared hopeless.

Desmond was not convinced that this situation could be allowed and tolerated especially when it was exacerbating both of his medical conditions and he decided to do his own research.

Desmond asked himself what term would he use to describe what his neighbours are guilty of and the term that came to mind was '**Antisocial Behaviour**'. Desmond was not good with computers and did not own one but, he knew about the internet and that it was a resource from which you could find valuable information. Desmond went to his local librarian for help and asked her to look up 'Antisocial Behaviour' (www.antisocialbehaviour.org.uk). This told him what constituted such behaviour and what an ASBO (Antisocial Behaviour Order) was. Here he found a link to the Antisocial Behaviour (Scotland) Act 2004 (www.gov.scot/publications/2004/10) and clicked on this. He clicked on the contents title and came to '**noise nuisance**' under part 5 of the Act and next clicked '**Investigation of excessive noise from certain places**' under '**noise control provisions**'. When Desmond clicked on this he found the following subtext:

Desmond found that:

"Where a local authority receives a complaint from an individual that excessive noise is being emitted from relevant property during a noise control period, it shall ensure that an officer of the authority investigates the latter matter".

"Where a local authority receives a complaint and the offending property is within the area of another local authority the first authority may act under the noise control provision as if the offending property were within its area".

"If an officer of the local authority considers that the noise coming from someone's home is more than, or may have been more than, the noise level allowed, they may issue a warning notice."

Desmond wrote to his Local Authority informing them that it was their responsibility to investigate the noise he had complained about and to take necessary action making reference to and enclosing the information that he had found on the internet. He sent a correspondence copy to his MSP. The Local Authority promptly went to the neighbours' house; thereafter Desmond was not troubled again by noise, nor did his neighbours ever verbally abuse him. He now enjoys quite nights and is no longer concerned that his epilepsy control might deteriorate due to the behaviour of others.

Desmond had confirmed that, under the Act, it was the responsibility of his Local Authority to investigate his rowdy neighbours. He had acted as an effective self-advocate with the help of a friendly local librarian. He achieved a successful outcome for himself with his neighbours no longer noisy or hostile to him.

8). THE EQUALITY ACT 2010.

The Equality Act 2010 replaced the Disability Discrimination Act 1995 and the 2005 amendment. The Equality Act 2010 differs from the Discrimination Act in that it covers all groups of vulnerable people who are at risk of discrimination thus protecting the rights of not just those with disability but also those from racial minorities, sexual orientation, age, gender and religion.



The part of the Act relating to disability includes:

- Introducing the concept of ‘discrimination arising from disability’
- Applying the concept of victimisation protection
- Describing what “the duty to make reasonable adjustments for disabled people” should mean
- Making it more difficult for disabled people to be unfairly screened out when applying for jobs by restricting the circumstances in which employers can ask job applicants questions about disability or health

The scenario below relates to the disability part of the Act.

Case Study 12

John was a support worker in the home of a man with cerebral palsy. John’s job required him to do shift work which involved working over 24hrs when part of the shift involved a ‘sleep over between 00.00-8.00am. John developed panic attacks where he awoke in the middle of the night in his allocated room, experiencing incredible distress and panic. This would then waken his client who would similarly become distressed. John’s nocturnal panic attacks were brought on by sleep apnoea (a condition in which oxygen to the brain was reduced by blocking of the throat whilst lying flat). This sleep apnoea developed, due to weight gain, while working for his current employer.

John’s employer informed him that it was too damaging to the client’s wellbeing as well as potentially dangerous for John to do the sleepovers. As a result he was told that he could no longer remain in their employment. John did not believe that this was the case as he felt he had all the skills, experiences and competencies required of him during his client’s waking hours and was sure that some re- arrangement of his work could be made in order to retain him as an employee.

John had heard lots of talk about ‘Gender Equality’ and thought that there must be as many rights for those with disability, living in mainstream society. John decided to search the word ‘**Equality**’ on the internet and came across a search result titled ‘**What is the Equality Act?**’ John clicked on this link and was taken to the Equality and Human Rights Commission(EHRC) website www.equalityhumanrights.co where he clicked on a link that took him to where he could view a summary of the Equality Act 2010 www.gov.uk/guidance/equality-act-2010-guidance

When John read this summary he came across the term ‘**Reasonable Adjustments**’. John then entered the term ‘**Reasonable Adjustments in the work place for disabled**’. www.gov.uk/reasonable-adjustments-for-disabled and this led to ‘**Workplace Adjustments: Equality & Human Rights Commission**’. www.equalityhumanrights.com/.../workplace-adjustments John clicked on this and was taken to a page providing guidance for employers on how to implement adjustments in the workplace as well as their legal obligation to do so.

John printed this off and arranged a meeting with his Manager as well as Head of Human Resources bringing this guidance to them. John’s boss, as well as human resources, agreed that more could have been done for him and that it would be in compliance with the Equality Act 2010 for his employer to allow for John’s 37.5hrs/week to be ‘awake’ hours and for another member of their staff, or agency staff, to cover the ‘sleepover’. John resumed work and a year later was promoted to Team leader.

John had been aware that there were rights to protect people in work who through a change in health could be in danger of losing their job though he had not heard of the Equality Act. By using the correct terms in searching the internet, properly sifting through the results and presenting them to his employers he saved his job by ensuring that the appropriate adjustments were made. By advocating in an amicable, informed manner he impressed his Manager and was soon promoted.

9). HUMAN RIGHTS ACT 1998



The Human Rights Act 1998 came into effect in October 2000 and protected the human rights of all civilians living in the United Kingdom. The Human Rights Act placed the European Convention on Human Rights into United Kingdom law. The Act ensures that all public bodies (such as courts, police, local governments, hospitals, publicly funded schools) and others that carry out public functions have to comply with the Convention rights. The Act sets out the fundamental rights and freedoms that individuals in the UK have access to. These include: The right to life, freedom from torture, inhuman or degrading treatment, The right to liberty, freedom from slavery and forced labour, right to a fair trial, respect for your private and family life, right to thought, belief and religion, right to freedom of expression, protection from discrimination in respect of these rights and freedoms, right to the peaceful enjoyment of your property, right to an education and the right to participate in free elections.

More information can be found at: www.equalityhumanrights.com

Case study 13

Jane has multiple sclerosis (MS) and was living in the ground floor block of flats where she was being bullied by her neighbours. The neighbours were making life intolerant for her by intimidating her as they saw her as an 'easy target'. Jane felt that the bullying campaign was aggravating the severity of her MS through increased stress. She had been to see her Housing Officer to report her problems on a number of occasions but no action was taken, on her behalf. The bullying continued and she felt a lack of interest or concern by her Housing Officer.

Jane's felt she had to look towards an alternative way in resolving the bullying. Jane noted that during her visits to the housing officer she did often use the expression that **"my human rights are being breached"**. Jane had heard about the **Human Rights Act** on the television, in conversation with others and in the newspapers and books. Jane looked up the 'Human Rights Act' on her mobile phone and was taken to www.liberty-human-rights.org.uk which told her about the Human Rights Act. Jane learned that the Act also puts an obligation on public authorities to protect these rights of their clients by taking any necessary action required to resolve their client's difficulty (www.equalityhumanrights.com/.../human-rights-act). Jane learned from this site that she should write a letter to her Housing Officer regarding her complaint and to mention that it was a breach of the Human Rights Act for him not to respond earlier and appropriately to her complaint. Jane also looked to see if there were any organisations that she could send a copy of her letter to (**See Correspondence Copy Section**) to put the housing officer in a position where he would feel exposed should he ignore her letter. Jane therefore searched **'Who oversees human rights in the UK'**. Jane clicked on the Wikipedia search result titled **'Human Rights in the United Kingdom'** where she learned about the Scottish Human Rights Commission (SHRC). Jane read their download (pdf) on 'help and advice'. When she wrote to her Housing Officer she sent her correspondence letter to the SHRC putting **"CC: Scottish Human Rights Commission, Governor's House, Regent Road, Edinburgh, EH1 3DE"** at the bottom of her letter so that the Housing Officer would be aware that the SHRC had received a copy.

After she had sent these letters, the Housing Officer took the necessary action, the bullying stopped and the ringleader of the bullying campaign, who had been the source of other earlier complaints, was threatened with eviction.

Jane had used the internet to investigate her human rights and found that these had been violated but no action taken. By finding out what these rights were in relation to inhumane treatment and private life she was able to convey this by letter to her Housing Office. With this and the appropriate use of a correspondence copy letter she was able to achieve, through her own self-advocacy, the desired outcome.

KEY POINTS

- When you “search” the internet select your question(s) carefully
- Try and identify which Law or Act applies to your particular case
- Try and find guidance notes – these are brief and less complicated
- Try and find websites that summarise the Act
- Don’t try to read the whole Act – that’s for the Lawyers
- Quote or print off what part of the Act you feel best supports your case

8. The importance of making Professionals ‘think outside the box’.

In our workshops, a common comment was that professionals often did not see beyond the single decision that they made and could not see the far reaching consequences or ‘knock on effects’ that might damage the individual. Workshop participants felt that this guide should contain a section and examples of how to get professionals ‘thinking outside the box’ as part of the self-advocacy process.

Often a problem that is not holistically addressed will cause other problems for you down the line. We call this the ‘**Knock on Effect**’. We want to draw professionals’ attention to the knock on effects of the decisions that they make. Looking at the long term consequences, and their potential costs, might lead them to reconsider their decisions. An effective self-advocate should draw attention to these possible outcomes in a truthful and non-threatening manner.

The following are examples discussed by workshop attendees:

Example 1.

Your Doctor wants to try you on another drug for your epilepsy because you have had a recent single isolated night time seizure. The doctor and you both know that the risk that changing treatment could backfire and cause an increase in seizures, especially during the daytime. The doctor tells you not to worry: if there were to be an increase in seizures then he would put you back on your old drug regime and nothing is lost. The doctor sees no other issues when thinking about changing treatment so, it is up to you to self-advocate your concerns about what the knock on effects might be if such a treatment decision is made.

Worse outcome: Increased seizure frequency results in you to having a seizure during day at work. This causes you to lose your job, lose your driver’s license (you must be two years free during day, or one year completely seizure free). Your job loss causes you great financial concerns and the recent daytime seizure puts a serious limit on the number and type of jobs you can apply for. This puts a strain on your family. All of this leads to depression and anxiety about future, causing further anger, loss of friends and the risk of your partner leaving you.

The above are the potential **secondary issues** (knock-on effects) that the **primary issue** (a single isolated night time seizure with change in drug treatment) could create for you. Too often, doctors will concern themselves only with the primary goal of getting you seizure free; they do not consider the secondary issues that, should they arise, are not so easy to rectify as the primary one (putting you back on your previous treatment). It is by making the doctor aware of the secondary issues that you can persuade him or her to reconsider their decision or else allay your fears and anxieties.

Voicing your concerns about the secondary complications of a treatment decision, by using self-advocacy, makes sure that you are part of decision making **for you** rather than being the onlooker when decisions are made **about you**.

This principle is potentially true for all professional-client relationships. Decisions should not be based on the primary issue alone but must take into consideration all the potential consequences .It is **easy to restart a drug but much more difficult to restart a life**.

Example 2.

Your old house is being demolished and a Housing Officer is moving you to a house in a street where you used to live as a child. The street you are being moved to is associated with an unhappy childhood and traumatising family relationships. The decision to move you to that street could have a huge knock on effect upon you. Your Housing Officer may be aware that moving you back into this street (**primary issue**) will remind you of the past but may not consider the consequences (**secondary issues**) of such a move. You decide to self-advocate by writing to the Housing Officer. It is important that when you write your letter, asking them to consider moving you to an alternative street, you make them aware of these **secondary issues**.

You might want to mention some of the following in your letter:

- Thinking of the past will make you angry, exacerbating depression and trapping you in a vicious symptom cycle where more reflection on the past causes more depression, causing more reflection and so on.
- Depression could hinder your ability to hold down your new job; the irritability that is a symptom of depression could affect colleague relationships.
- The increasing anger and irritability could affect your relationships with family and friends.
- Living across the road from where you had a traumatic childhood will only make you feel trapped and helpless bringing on feelings of anxiety that can develop into attacks of panic.
- The mental health problems will inevitably have an effect on your physical health: exacerbating any existing physical health conditions.

A letter mentioning some of the above makes the Housing Officer think “outside the box”. It makes him/her think beyond their initial straightforward decision to move you to that street and to consider the complex effects that this decision will have.



With your letter you should provide evidence that supports the claims you make; for example a letter of support from your Doctor or any other healthcare provider that you might be attending e.g. psychologist etc. Your letter must be truthful and not over dramatize the situation. **Don't cry wolf!**
–Don't cry or complain about something when nothing is really wrong.

Example 3.

Ms X has arthritis and other complex health problems. She uses a wheelchair about her house. She is capable of standing out of the chair and walking a few metres, before her blood pressure drops and she gets dizzy spells and needs to sit back in it. She has a carer visiting her once a week and there are ten steep steps up to her main door. She has no ramp, her wheelchair is manual and there is no one available to come and take her out other than her once a week carer. She has neither family nor friends. She has asked Occupational Therapy to provide a ramp but this has not been sanctioned. She believes that this is because of the height of her steps and building control regulations despite a similar house in her neighbourhood having a ramp. She says that the Occupational Therapist has told her that her only option is to move but she has lived in her house since childhood and does not want to move. She has been declined an electric wheelchair and her application to increase her hours of care has been turned down by social work.

She has argued that if she had a ramp and an electric wheelchair she would be able to leave the house independently and not be 'housebound', six out of every seven days

The **primary issue** is whether to supply a ramp and electric wheelchair. The **secondary issue** is the consequences (and potential costs) if it is decided not to do so.

When making her case in writing (self-advocating) to the Occupational Therapist, for a ramp and electric wheelchair, Ms X must mention what she truthfully sees as the **secondary issues** that will arise should the decision go against her. In this she must try to support her claims with correspondence from her Doctor or another health carer. Her letter must be balanced and not seen in any way to intimidate. With threat of "if you don't give me this you are to blame for all that follows"

Someone in Ms X's position might consider mentioning some of the following secondary issues when self-advocating to her Occupational Therapist:

- Social Isolation brings on feelings of helplessness and hopelessness and panic which with time can develop into panic disorder
- Social Isolation causes lack of mental stimulation which causes boredom, causing you to reflect on how unhappy you are with life, resulting in more reflecting, causing more depression.(the vicious circle again).
- Getting out is important for wellbeing as you feel 'socially connected' when meeting people in the streets, cafes, clubs and societies.
- Sitting in a wheelchair in a house on your own, 6 days a week, is just existing and not living.
- Social isolation makes pre-existing mental health problems worse and increasing the cost of healthcare but also increases an elderly person's chances of worsening dementia.

When writing a letter to help professionals 'think outside the box' on your behalf, when making decisions or when you are trying to reverse a decision already made, you should:

- a) Identify the problems that the decision might cause you. Your secondary issues.
- b) Research and think through the effects that your secondary issues might have upon your health (physical & mental), employment, education, relationships with family and friends, independent living skills e.g. driving, finances, hobbies & interests and future plans etc.

Some of the information on the above you will already know and be able to write about in your letter, however you may have to do some research on the internet, in the library, through discussion with a charity helpline or with your doctor or other health professional etc.

KEY POINTS.

- It is your right to point out all the consequences you see of any decision professions are considering
- Be truthful and don't exaggerate
- Don't 'cry wolf'
- Don't threaten or blackmail them into the decision you want
- Back up your comments with evidence and letters of support

9. Attending meetings.



General comments:

- The meeting is not **about** you but **for** you to help you address your issues
- Be sure that it is organised for a day and time that suits you
- Highlight any accessibility needs you have in advance
- Make sure you know exactly where the meeting is going to be held and who will be there. It is best to get these details in writing
- Do your homework and remember to bring it with you
- Don't be late
- Say in advance if you are bringing someone to the meeting to support you
- Stick to the point of the meeting (Don't go '**off-message**' or discuss unrelated issues)
- Don't take over the meeting, let others have their say
- Listen to what others have to say and acknowledge what they've said, even if you don't agree
- If people use professional jargon, say that you don't understand and ask them to avoid using it
- If others interrupt, take over or talk about things that you see as irrelevant, it's OK to ask them to let you finish or get back to the point. For example: "If we could get back to what we were talking about" or "Can we stick with the topic?"
- If people are talking over you, you can use statements such as "if I can finish what I was saying..." or "Please let me have my say"

Throughout be **polite**, **focused** and **non- confrontational**. Never make threats. This approach will best help your case.

Preparing for the meeting:

Prepare notes that will cover everything you want to say at the meeting.

Write down **1) what you want to achieve, 2) what you want to say, 3) what order you wish to say it in, 4) what supporting evidence you are going to use to back up your arguments.**

Supporting evidence could be in the form of:

- Symptom Diaries i.e. dates and times of symptoms and the effects i.e. limitations/restrictions these symptoms have had on you.
- Information from the internet from reputable sources such as scientific and medical journals or Charity websites
- Information from the internet or Citizens Advice Bureau or by telephone helplines that give you information on relevant rules & regulations, Codes of Practice, Policies and Procedures and Guidelines.
- Witness account in the form of a supporting statement, for example from health professional / carer/family or neighbour. Alternatively arrange for someone supporting your case to attend the meeting with you. This could be a friend, informal carer, spouse, other family member, someone from a voluntary organisation who provides you with a service etc.

At the meeting:

- Take written notes. Enquire about a scribe (someone to write notes for you) if you have difficulties with literacy and numeracy
- Read out your notes as you go along asking for confirmation, especially when a key point has been made, that your record and understanding of the meeting is correct
- If you are told that something is going to be arranged, ask for job title, name of person who will be doing the arranging and if possible the name and job title of the person carrying out the action. Also, ask how long you can expect to wait for the action to be completed. Again write this down and read back for confirmation
- Ask for a letter or e-mail of confirmation that this action was agreed so no one can deny this at a later date
- If you are cited policies, rules and regulations as an excuse for someone not doing something for you then ask for copies of these rules and regulations and departmental policies
- Consider taking a witness to the meeting. This is especially important if you are anxious and liable to forget what was said. The witness could act as your Scribe as often it is difficult to write and listen at the same time – especially when flustered
- Write down any agreed plan of action, in terms of moving towards resolution, and read this out to the person heading the meeting to get confirmation of its accuracy

After the meeting:

What happens after a meeting is almost as important as the meeting itself:

- If you promised during the meeting to get back in touch with additional information, be sure that you do so. Failure to follow up on your promise will call your credibility into question and delay any outcome.
- Send (by mail or email), to all those who attended, your minute (record) of the meeting and ask for confirmation on its accuracy.
- Ask for written confirmation of the agreed outcome of each discussed aim and objective so there is no misunderstanding.
- Stay informed on your issue and track how your authority responds. Did they follow through on promise made? If not, request an explanation. If so, express your appreciation.

10. Confidence building and stress management.



Earlier in this guide we briefly covered **cognitive techniques to empower the self-advocate**. In the workshops, attendees stressed the need for **confidence building** to help them in their self-advocacy efforts. **This section enlarges upon the earlier one but with the emphasis on confidence building.** To be a self-advocate is very much like a being a driver. You need to have confidence. Confidence gives you the energy to resolve your problems. Confidence is self-belief and self-belief is what makes you get up and try again to succeed, if you are not successful on your first attempt.



Survival of the fittest' is an innate human trait sometimes leading people, in an authoritative relationship over you, to pick up on your vulnerability and lack of self-confidence. Exploiting this vulnerability creates an uneven playing field. Policy makers are tempted to make austerity cuts to services and the benefits of people with disabilities before other groups as they see such people as being the least likely to complain or articulate their case effectively . It is for this reason that it is vital that you have confidence as it is the detection of low confidence and the inability to fight your cause that could lead some to think that they can deny you a service or a treatment that you are entitled to.

There are many ways in which you can address low confidence other than by psychotherapy and, by doing so, you can become your own therapist. What follows is a list of techniques that you can use to build your confidence. These methods have been the subject of many academic studies that demonstrate that they have significant cognitive (mind) effects on confidence building. These techniques are sometimes life changing for the individual. They are not just used for confidence building but some of them can be used for combatting anger/rage, anxiety disorders as well as depression.

Meditation.

When we are asked to do something that makes us apprehensive, fearful, angry and defensive, we find it hard to stop these negative emotions taking control and limiting us in the way we effectively perform. You can use meditation to control these negative emotions and to eliminate them.

If we are asked to attend a meeting and to speak up on our own behalf we become nervous because we worry about all the things that could go wrong (**negative thinking**).



- What if I forget my words?
- What if people get bored and stop listening?
- What will people think of me when I stand up in front of them and speak?
- What if my voice starts shaking and I start sweating?

These are all uncertainties that are focussing on the **future (imagined worse outcome)** and not the **here and now** as you have not yet begun to speak. These thoughts backfire on us and we lose our concentration by not focusing on the here and now. We forget our lines; we start becoming rambling, hesitant and inarticulate and our voice starts shaking because we are full of adrenaline. We hear our voice shaking and things go from bad to worse. At the end of the meeting we feel that we have damaged rather than helped our case and that the professionals we have been speaking to may be left thinking that we are an inarticulate fool which we are not!

Because of these worries, many clients don't want to say anything at a meeting. They feel that no-one will take their contribution seriously so, what is the point? Because of this, they have failed to self-advocate. How can they make matters better at future meetings?

Future thinking (imagining the worst) influences your ability to perform and feel comfortable in the present moment. How do you combat it? Through **Meditation**.

Meditation is a technique that involves concentrating on your breathing. There are many websites that give advice on meditation. For example (zenhabits.net/meditation) is a useful guide introducing beginners to the basics of meditation

Meditation involves:

- Sitting down, closing your eyes
- Ridding your body of all muscular tension
- Slowly focussing on your breathing

Focus on your **in- breath** - air entering through your nose/mouth, and entering your lungs. Focus on the depth of the in- breath. Then focus on the **out- breath** - feel of the air leaving your lungs as well the depth from which the air has come up.

While you concentrate on your breathing,

- Let your thoughts flow through your mind like clouds in a sky
- Don't engage with any thoughts, just empty your mind and ignore them, focussing on your breathing as the thoughts pass away
- Your mind will naturally wander and engage in thoughts but when you become aware of yourself doing this, return your mind to your breathing
- The durations of '**inner silence**' will become greater and greater as you get more practised at the technique

Meditation should be practiced **twice a day for twenty minutes at a time**, preferably morning and night. By focussing on your breathing, and ignoring the inner thoughts, you will train your mind to stay in the present moment and stop your mind from straying into the future zones that hinder performance.

The length of time that it takes for an anxiety or phobia (A phobia is a type of anxiety disorder where you have an excessive fear of a certain object or situation) to be eliminated by meditation depends on how ingrained this is. A 40 year old who has phobias that go back to his school days might require months of meditation but one that has developed more recently would not take as long. The universal anxieties, i.e. anxieties that affect more or less everyone such as speaking up for one's rights against an authority or giving a presentation, can be overcome in days. Meditation can be used to manage anger and rage. Meditation stops you from going home, after having met someone who has hurt your feelings, and not dwelling about what you should have said or done at the time. It keeps you in the present ridding anxiety and enhancing self-confidence.

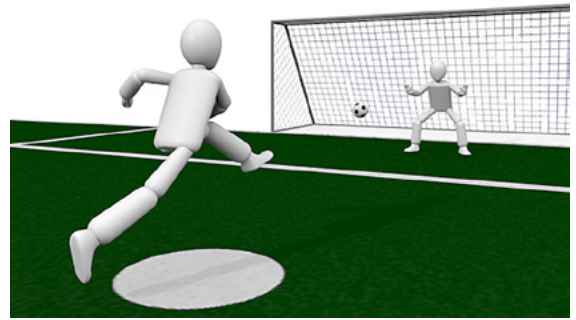
Visualisation.

Visualisation is a technique used to overcome phobia and the negative emotions that can hinder your ability to perform well and feel comfortable when carrying out present moment tasks. Detailed information can be found at www.successconsciousness.com. Visualisation will increase your belief in performing successfully and thus promotes self-confidence. It is a technique frequently used by successful sports stars and sports psychologists.



Creative visualization is a mental technique that uses the imagination to help us create what we want in our lives.

Visualisation is also known as '**Mental Rehearsal**'. The mind is made to have difficulty knowing the difference between reality and fantasy. The mind can be fooled into believing it has done a task previously with success and therefore the task can be done again in the future with the same result. There are the **two basic steps** to improve our visualisation skills. The first is to **relax** and the second step is to **visualise**: seeing yourself achieving what you want, with confidence and success.



Belief is the most important part. If we can see it (with visualisation) we can believe it and achieve it.

During creative visualization it is also important to picture everything from **the first person point of view through your own eyes**. Include all the details of what you desire, see it in the present tense and allow all your senses to experience the image.

The following is a simple example of how creative visualisation helped someone to combat the fear and anxiety when confronted with their driving test.

Case Study 13

The week before Dominic's driving test he was worried that it would all go wrong as he had performance anxiety due to past experiences. He lay on his back, shut his eyes and saw himself getting out of bed on the day of his test and feeling confident. Dominic pictured himself arriving at the test centre, determined that no anxieties would affect his performance. He visualised the whole process of going through his test culminating in the driving instructor saying "Well done! You passed!" On the day of the test Dominic felt confident, excited and ended up feeling overjoyed at passing his test.

Visualisation can be utilised during the self- advocacy journey. Visualising success draws success into people's lives. If you want something badly, so long as the goal is realistic, visualising its attainment greatly increases the odds of you getting the result you wish. Visualisation does this by fuelling you with motivation and determination to put every effort you possibly can into achieving the result that you want. You should see images in your mind of you achieving your outcome. You should see yourself do it in your mind just like Dominic did with his driving test. You must keep all negative images out of your mind. If you see negative images of failure intruding, you should see them 'explode in your mind, being immediately replaced by positive ones.

The 6 steps of visualisation are:

1. Decide exactly what you want.

To get what you want, you need to know what it is

2. Relax.

For success, you need a focused mind. Clear your mind of all thoughts and relax

3. Visualise.

Get clear about what you want. Imagine it very clearly as if you have already achieved it

4. Send the positive energy.

Creative visualisation and positive thinking are inseparable. Always focus on the positive image

5. Use affirmations.

Affirmations are one of the most important elements. Affirmations are a positive statement of acceptance of our goals. Affirmations are always in the present tense

6. Believe.

Thought Blocking.



This is a phenomenon that occurs when a person's speech is suddenly interrupted by silences that may last from a few seconds to a minute or longer. Blocking is often brought on by questioning or discussing something of particularly large personal significance. When the person begins speaking again, after the block, they will often speak about a subject unrelated to what was being discussed before blocking occurred.

Often, when trying to resolve a conflict/problem/issue that you have with another party, you have thoughts about not succeeding and being worse off, after your efforts. This is especially the case if previous attempts have resulted in such outcomes. Very often these thoughts are accompanied by an image of failure in your mind.

These thoughts are very often involuntary; they just appear and undermine your confidence as well as your efforts thus inhibiting your ability to be the best self-advocate that you are capable of being. This impairment can be countered by pushing these thoughts out of your mind, immediately after becoming aware of their presence, and replacing them with positive outcome thoughts. This will train the mind into becoming a habitual positive thinker thus filling you with determination and motivation, to be the best self-advocate you are capable of being. The odds of a favourable outcome, in your attempts to seek resolution, will be greatly increased.

- The first step to blocking an unwanted thought is to say "I don't really need to think this"
- The second step is to replace the unwanted thought or feeling with a positive one that relates to the situation that you are in

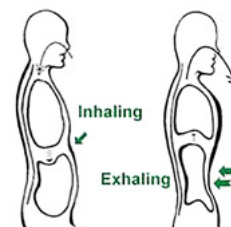
We shouldn't block all the unpleasant thoughts that come our way. There are times when we do need to reflect upon the bad things that happen to us so that we learn and grow from our experiences.

Advice of techniques to prevent thought blocking or to replace negative with positive thoughts can be found at: www.getselfhelp.co.uk/docs/FindingAlternativeThoughts.pdf. and www.calmclinic.com/anxiety/symptoms/unwanted-thought

Slow Breathing.

Slow breathing can be used to calm you down whenever you are experiencing anxiety episodes especially panic attacks. Many self-advocate situations can bring on feelings of helplessness and hopelessness and this may result in feelings of panic and even panic attacks. Containing this enhances self-confidence.

The symptoms of a panic attack are as follows: dizziness, light-headedness, lump in the throat,



fatigue, poor concentration, choking sensation, racing heart, shaking, blurred vision, chest pain, disorientation, tingly sensations or numbness in the hands, feet and mouth.

It is not difficult to see how panic might affect our performance at a meeting when decisions about our future are being discussed.

Panic Attacks can have such a crippling effect on a person's life and are brought on by the '**flight or fight**' response. This response is our body's primitive, automatic, inborn reaction to prepare us to 'fight' or 'flee' from perceived harm or threat to our survival. This response results from the release of chemicals such as adrenaline, noradrenaline and cortisol into our bloodstream and their effect upon our brain.

The brain can be misled, like the mind can, and convinced into believing there is no threat. You can do this just by breathing slowly in and out. This will immediately fool the brain as it associates slow breathing with being in a relaxed state. This immediately makes the brain feel it should be feeling relaxed. When the brain is relaxed, the state of panic defuses. Slow breathing could be used for panic attacks in the same way that an inhaler is used for asthma.

When you are first attempting breathing relaxation exercises it is easiest to lie flat on your back, knees bent, feet flat on the floor and eight inches apart then -

- 1) Place one hand on your chest and one hand on your abdomen
- 2) Hold your breath and count to 10
- 3) Breathe out and think 'relax'
- 4) Breathe in slowly through your nose for 3 seconds
- 5) Breathe out through your mouth for three seconds, making a whooshing noise as you breathe out and think 'relax'. Repeat 6 times then hold your breath for 10 seconds
- 6) Keep repeating this process for 5 minutes

Breathing exercises can help with a variety of anxiety issues such as a fear of public speaking. Further information on breathing techniques and anxiety can be found at www.anxieties.com/

Exercise.

Exercise can be used to boost confidence, alleviate anxiety and fight depression. As little as 3 hours of exercise a week is enough to have significant effects on state of mind and wellbeing. There are two types of exercise:

Aerobic exercise is exercise such as running, cycling, swimming, cross training, rowing etc. where you exercise for a minimum of twenty minutes.

Anaerobic exercise is exercise that focusses on strength more than fitness and involves sudden, short duration, high intensity activities such as sprinting or weight lifting.

Both types of exercise increase chemicals in the brain called **endorphins** and these can produce feelings of confidence as well as bringing on an increased sense of wellbeing. Endorphins also have anti-depressant as well as tranquilising properties. The resultant wellbeing could transform an ineffectual self-advocate into an effective one. Exercise also boosts morale and self-esteem and therefore makes you much less defensive and less likely to take things personally - essential qualities when you are trying to self-advocate.

The American Heart Association recommends the following regime for health living:

- At least **30 minutes of moderate-intensity** aerobic activity at least **5 days per week for a total of 150 mins**
- OR
- At least **25 minutes of vigorous** aerobic activity at least **3 days per week for a total of 75 minutes**; or a combination of moderate- and vigorous-intensity aerobic activity
- AND
- **Moderate- to high-intensity muscle-strengthening** anaerobic activity at least **2 days per week** for additional health benefits.

www.heart.org/HEARTORG/HealthyLiving/PhysicalActivity/

Distraction.



Distraction is a technique that can be used as a form of anger management, anxiety control, and depression management. It also is used in the management of pain especially in children. It works along the principle that the mind can only think of one thing at any one time. Our emotions, as has been demonstrated in the other techniques this guide has introduced you to, are controlled by our thoughts. When using distraction we substitute thoughts. If what someone said to you fills you with anger then just stop thinking about it and think about something else. **Visualise a waterfall** and hear the water flowing. Focus on the sounds and colour (aqua blue) and the scenery around the waterfall such as mountain tops and this will take your mind off what is making you angry or even how you are going to pay an outstanding bill! **It's like watching the television. If you don't like the channel, change it!**

Other useful distraction techniques include:

- Count backwards from a large number by sevens or some other number.
- Focus your attention on your environment. Name objects with the same colours in the room.

Try to come up with your own list of distractions that you can use when you experiencing a strong emotion that is proving difficult to cope with in the moment.

More information can be found at: www.throughthecLOUDS.moonfruit.com/distraction...

Positive Affirmations.

**I AM IN
CHARGE
OF HOW I
FEEL AND
TODAY I AM
CHOOSING
HAPPINESS.**

Positive affirmations are positive statements that we say about ourselves to ourselves. Unfortunately and too often, much of our internal dialogue about ourselves is negative. Sometimes we are the very person who puts us down the most. This negative dialogue destroys our confidence and our self-esteem. We have become our own worst enemy.

Too often when people are trying to tackle a problem, they complain that "I can't do this"; "This will go wrong"; "This will be a disaster"; "I am too weak to do this". These statements make your campaign a losing battle before you have even started. Any football team going onto the park saying "we are bound to lose" will lose 9 out of 10 times. On the tenth time they win, probably because the other team has had the same negative attitude!

Like visualisation, positive affirmations have you say positive things about yourself in the past tense so that the things you wish to achieve have already been achieved in your mind's eye. This will program your mind into believing that you have already achieved your goal. This will boost your confidence and make you more likely to achieve your desire of representing yourself to the best of your ability. Thus by fuelling your motivation, confidence and determination you are giving yourself the drive to succeed at being a good self-advocate.

You should personalise your affirmations as much as you can such as putting your name in them and each affirmation should have a positive word in it. Examples of good positive affirmations are:

"My name is **Margaret** and I **succeeded** at getting the housing association to move me and my family into a better home"

"My name is **Margaret** and me and my family are living in a much better house living a very **happy** life"

"My name is **Margaret** and I have been a **successful** self- advocate who got her family moved"

You can think of a few others to fit your circumstances. It is probably good to have five or six positive affirmations in your mind when you are facing a self-advocacy issue.

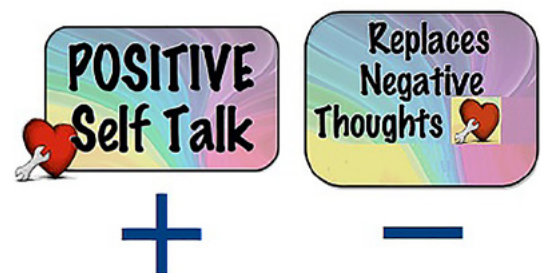
Like visualisation, it is vital that you keep all **negative affirmations** out of your mind. If you hear any, make them '**explode**' and say all your positive affirmations to drive them away for good.

More information can be found at: www.vitalaffirmations.com/affirmations.

POSITIVE SELF- TALK

This is similar to positive affirmations though it is not made up of statements but rather is an internal conversation where you compliment and praise yourself for your positive attributes and tell yourself that good things are going to happen. Again you must keep the 'bully boy' negative self-talk out of your mind by making such talk '**explode**'.

It helps to **rephrase negative self- talk**. Phrases enter your minds that are full of negative commentary. Every time this happens you should listen to the conversation and rephrase it so that it is now telling you something positive and your inner self dialogue begins to sound positive and upbeat.



You are the doorman or 'bouncer' of your own mind. Remember that you have to keep the bully boy from getting in or get him out or change his message!

Reading Therapy (Bibliotherapy)



This involves the use of reading to aid healing and has been shown to be effective in the treatment of depression and anxiety, results having been shown to be long-lasting

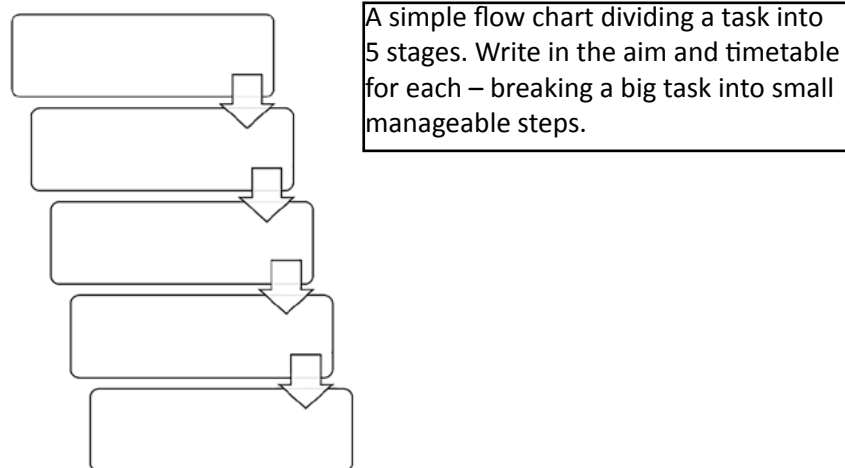
Very often the conflict or problem that you are faced with can preoccupy your mind for very long periods of time and you feel that you are never getting away from it. This results in you becoming increasingly stressed and burned out. To have the problem on your mind the whole time, or the vast majority of the time, escalates anger, frustration, agitation, depression, and anxiety etc. which build to such a magnitude that your mental state cannot cope. It is for this reason that you need to be able to **escape** from the problem, recharge and defuse any ill-emotions that are damaging your life. There is a danger that this mounting anger could be unleashed at a meeting, giving professionals good reason to refuse to meet with you again and so denying you what you feel to be your rights.

Escapism is the tendency to seek distraction and relief from unpleasant realities, especially by seeking entertainment or engaging in fantasy. It is a technique used to give the mind a break from a problem, issue or conflict. By reading a book, the story of which is based in a time and place far removed from where you currently are and by imagining yourself to be a fly on the wall, in that time and place, you can take yourself away from the problems that you face on a daily basis. By taking this 'time out', you will feel recharged and feelings associated with depression and anxiety may be diffused.

More information can be found at: www.storiedmind.com/psychotherapy/reading-depression-therapy

Managing memory, lethargy and fatigue.

Frequently the drugs used to treat a neurological condition can affect energy levels, resulting in **fatigue** and **lethargy**. This can impair your ability to self-advocate by making it impossible to find the energy to write and send letters, make phone calls, respond to replies and search for information. One way to overcome this, as already discussed, is to meditate. Another way is to **break down tasks** into small manageable stages by putting together a plan of action and an achievable timetable for you to follow. The thought of resolving a complicated issue can feel like a **mountain to climb**, especially if you can't see how you are going to get from present moment to achieving future resolution. To overcome this you should think out the steps you need to take and construct a **flow chart** to show these steps and the dates that you plan for each stage.



Seeing this gives you a feeling of control and reaching each stage gives you a sense of achievement. Now you will see the obtaining of resolution as being a number of small consecutive steps as opposed to one huge jump. The job seems less daunting and this will inspire, motivate and fill you with determination and minimise the effects that lethargy and fatigue have on your ability to perform.

The overall management of fatigue itself is complex and out with the scope of this guide.

Useful advice can be found at: www.brainandspine.org.uk/fatigue-and-neurological-conditions

Many neurological conditions, especially those of the brain, result in impairment of **memory**. To overcome the hurdles that this creates for you, you should keep a diary of every action you have carried out, every outcome that has been achieved as well as continuing to make reference to your flow chart (see above). You should also take notes at any meetings as well as prepare notes before going into a meeting of the things you want to say and have addressed. (See preparing for meetings).

Coping with memory problems is complex and often depends on the underlying cause. Concentration is another function that can be impaired by neurological illness and the medications that are used to treat it. Advice on strategies to help memory and concentration in brain injury can be found at: www.braininjuryeducation.org

The described cognitive techniques, whilst applicable here to self-advocacy, can also be applied to any other challenging situation that could enhance your quality of life and prospects of success or avoid an unwanted situation arising. These techniques are transferable to many other areas of your life such as dealing with depression or anxiety disorders, excess stress, preventing relapse of an established mental health problems or dealing with dependency. Cognitive techniques can improve the chances of success at any life challenge thrown at you.

11 Conclusion.



You may have read this self-advocacy guide from cover to cover or else just dipped into a section you feel relevant to your situation. Whichever you have done, you will have realised by now that the important skills for successful self-advocacy are **confidence**, **knowledge**, **problem solving** and **communication**.

Of these **confidence** is the major ingredient of good advocacy with all other skills flowing from it. Confidence shapes the winner's attitude that brings results. No football team wins a match when its mind is full of images of losing goals with the manager shouting in the changing room and tomorrow's newspapers broadcasting its defeat. No one will ever win if their inner dialogue is full of negative self-talk putting you down and destroying your confidence.

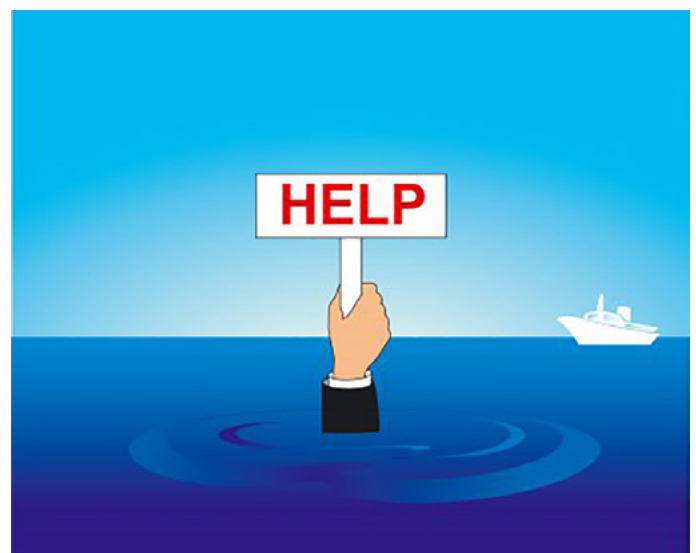
The value of gaining and retaining confidence is one of the most important messages to take from this guide. Hopefully it has provided you with the tools to acquire confidence not only to aid self-advocacy but also to be transferable to all areas of your life and wellbeing. Confidence doesn't just enhance your capabilities and potential when it comes to self-advocacy but it can also unleash these when it comes to your job, a sport that you play, a college course that you are on, and other performance settings that you find yourself in.

The next most important skill is that of **communication** (confidence being essential for good communication). Relationship formation is driven by communication, the success or failure of which determines its positive and negative aspects. Good communication will allow you to form positive relationships with people who are offering you support and will thus want the best for you. Keeping communication amicable is important in getting your case heard and appropriately resolved. Any decision made is heavily influenced by quality of the information given and how it is communicated. What you feel is an unfair decisions made by a person in a position of authority may stem from a breakdown in communication. Remember that it takes two for this to happen and it's not always the other person's fault. Keep communication amicable, informative, relevant, coherent and as articulate as possible. Good communication results in friendly positive relationships ensuring that those involved in decisions relating to your wellbeing and rights do so wisely and are well informed.

Knowledge and problem solving feed off one another and can be considered as a 'double-barrelled' skill. It is these abilities that provide you with the '**best evidence**' needed to resolve your issue. The problem solving approach can be broken down into:

1. Determining what you need to know, followed by,
2. Finding what you need to know, followed by,
3. Learning what you need to know, followed by,
4. Applying to practice what you have learned.

This approach to resolving an issue is one that is transferable from the role of self-advocacy to many other aspects of daily living involving the acquisition of information. For example you would use this same approach when you needed some basic IT (Information Technology) skills to apply for work and prefer to take responsibility for your own learning (self-taught). In this situation you would ask a friend or relative in employment what kind of tasks they carry out on computers on a daily basis. You would then ask this friend how they would go about doing each task and learn the terminology from them. Now you know what you need to learn and can set about how to find the information (books, online) that will help you achieve these skills. You might ask your friend if you could practice on his computer until you gain fluency in these IT skills i.e. Microsoft, internet searches and setting up and using e-mail, all the IT skills that you need in order to apply for the job.



Never be afraid to ask for help. This is 'easier said than done' when confidence is low and anxiety high. Starting on the road to self-advocacy and to any type of self-management often needs a **kick start** from others

CONFIDENCE BUILDING, GOOD COMMUNICATION, KNOWLEDGE & PROBLEMSOLVING are skills essential for effective, successful self-advocacy and are transferable to dealing with many of complicated problems that can appear in the life's of those with long term conditions. These skills are not just limited to resolving problems thrown at you but they are also transferable to enhancing your general life experiences. This guide, as well as teaching self-advocacy, also aims to teach the valuable life skills important to the wider self-management of those with neurological and other physical long term conditions.

Fairway Advocacy is confident that this guide can be used by many to help them become self-sufficient self-advocates capable of getting fair, just outcomes and recognition of their rights. We are also confident that with the correct usage and right attitude this self-advocacy guide can be used as a life coach. All the skills, techniques, and processes described here are transferable to the many different predicaments that arise in so many other areas of a person's life.

Tim Bone on behalf of Fairway Advocacy
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