



Helpful Hints to be Inspired to Do It Yourself

To achieve any goal, all it takes is one step at a time. With my recovery, I had to find each step myself which took patience, persistence, determination and tears. I had no guidelines, no information and no direction except my strong willpower and my independent nature.

I want to help others and give them the basic steps to start their journey. This is for you and our loved ones and your carers. Firstly break it down into 3 easy steps:

1. How are you now?
2. Where do you want to be?
3. What steps you need to get there.

Then take the time to find out more about yourself. What to look out for. Things you can do to help and where to look for help. I like to start with the basics which may sound easy but I assure you that they are more complex than first thought. Always make a list as this is great for remembering to ask questions when visiting the doctors and specialists.

1. How are you now?

Firstly list all the physical problems and then we look at behaviours, memory and sensory issues.

Here is a list to help find out how you are and what your triggers maybe:

1. Disorientation – do you easily get lost or forget which direction you came from?
2. Memory issues are they short term memory or long-term memory
3. Coordination problems which include balance and spatial recognition. While you are standing, close your eyes and touch your nose. Did you wobble and did you find your nose? Spatial recognition is more about being aware of your surroundings and gauging distance. Can you reach out and pick up your glass without bumping it?
4. Hearing – are sounds too loud, too soft or too much at once? These can cause anxiety and confusion. I use music with an earplug in the one ear that is affected to help me cope with sounds being too loud.
5. Vision – this can be trying to identify everything in your vision which overloads your brain. It can be that fast movement is too much as you can't grasp what you are seeing which over stimulates the brain. It can also be distortions in your vision. I had the floor and walls move like waves which frightened me but we found out that it was only my brain reconnecting itself.
6. Sense of smell – check this as it took ages for anyone to pick it up with me. If you can't smell anything, be aware of how your body react to the smell. I believe that when I smell something, the information goes to my brain, the body reacts to the smell but it doesn't return the smell back to my sense of smell. Now I smell something and wait for my body to react which could be in survival mode where your body reacts like it smelt a chemical and therefore dangerous. Shoulders up and you recoil. Another response is like when you smell a flower and you smile and relax. So much of the brain to learn and understand.

7. Sensory issues – the brain has to cope with so much at a time. Imagine watching television while sitting on a chair in the lounge. Firstly your feet touch the floor and they feel the coolness of the tiles. The back of your body feels the warmth of your chair and the softness or firmness of the chair. Now the fan is going and you hear the noise of the fan and feel the breeze on your body. Your hair is moved by the breeze which gives another sensory feeling to cope with. The television is on and you concentrate on the sound and words being spoken and the movement and story on the screen. Your body has to regulate its temperature with the coolness of the fan. We all do this without thinking but when you have a brain injury, your brain is trying to cope with it all at once. Sometimes you don't cope with it and it's a sensory overload.
8. Communication – covers what to say, how to say it, when to speak, interacting with others. Do you understand what people are saying? How do you cope with the tone of their voice or the emotion behind the words? Do you look at facial expressions to help you understand? Give your brain time to process everything. If someone asks you a question, you can easily say 'Give me a minute to think about that.' Or 'I'm not sure what you are asking me.'
9. Emotions – these are all tied together and it can be confusing to work out how you feel with everything. Take a moment to look at other factors like are you safe, are voices raised, are you in pain or someone else in pain. Also be aware of how your body is responding to the emotion as you stand tall and breathe deeply in a strong stance. Maybe your shoulders are curled forwards with your arms protecting your body. These cues help to understand what emotion you are feeling.
10. Body temperature – many of us have difficulties regulating our inner body temperature so be aware that you may need to cover or uncover your arms or legs as needed
11. Social interaction – are you ok going out? Do you need strategies in place to help you? It could be someone to go with you. Knowing the layout of the place you are going to. Having information of who is going, when you will be leaving and what is happening when you are there. These might only need to be verbal and explained in the order it happens which will help you cope.
12. All learned behaviour – I had to relearn all of this which seemed an endless list of things. When to eat, how much, when to go to the toilet and how it feels to need to go to the toilet. Where to sit at any event including at the doctors. Think of a child and what we teach them from birth. You aren't childlike but it helps to be aware as you relearn your body's feeling and reactions. I had morning tea at 10 am so I will probably need to go to the toilet at 11 am. Instead of busting to go to the toilet like before, I notice that I feel different in my lower abdomen and think, 'Maybe that is my bladder feeling full.' Off I go to the toilet and yes. I remember that feeling and next time I feel it, I know I need to go to the toilet. Relearning can be so quick and make life so easy.
13. Flexibility – this is physically and mentally. Can you easily adjust to changes? Do you cope with interruptions and recall what you were doing beforehand?

14. Sleep – I had to retrain myself to go to sleep which started with me counting sheep and I struggled with it. I sought help through reading which taught me a breathing technique and to relax. Dr Frank McDonald taught me the 3 second breathing technique. Firstly, he told me to say to myself ‘I am safe.’ As I breathe in for 3 seconds, hold for 3 seconds and breathe out for 3 seconds.
15. Grief – there are levels and steps of coping with loss and your grief. Understanding these steps helps your recovery. I found comfort knowing that what I felt was normal. This helped me to cope with how I felt.
16. Anxiety and Depression – they are real and it’s ok to talk about them and seek help. They caused me lots of grief and stopped me doing things, so I found ways to help myself and sought help from doctors and psychologists. One way was to imagine that I was floating down a creek. At first I tried to hold on to the sides of the creek which restricted me floating down the creek. I had to imagine letting go and enjoying being floated with the flow of the water. I’ve used this awesome technique for nearly 30 years. You need to find what works for you.
17. Acceptance – we need to accept ourselves which can be a journey in itself.

There is so much more that I could add to this list. We are all different so use this as a guideline. I ask you all to take the time to write your list, ask your questions and find the answers to be you again. When you feel that you have some control of your health and your life, it is one of the best ways to cope.

I remember sitting with my doctor, feeling frail, scared, anxious and that my world was ending. She talked with me, calmed me down and told me that I had control in my life. I could make my own choices and I had every right to ask questions. By handing me control of my life, she empowered me. It made me feel stronger and I knew I could take control. I’ll never forget her understanding and I thank her.

One of my favourite saying is that information cures fear. When I find myself worrying about something, I go and research it and find the answers.

2. Where do you want to be?

Write down your goals and list everything you can as this gives you a reason to find the answers and helps you to focus on the future. Take control of your life.

3. What steps you need to get there?

Look at each goal and identify each step you need to reach it.
These steps can be as small or as big as you want.

One of my goals was to write my own story to help others. I took it one step at a time, one page at a time. Please take my advice that you don’t have to do this alone. Find the right person to help you with each step of your recovery so that you reach your goals.

I am here to help you. I may not have all the answers but I can listen and together we can find the answers. I wish you all the best.

Live the Life you Love Sandra