



# Making the most of later life with Epilepsy

## A Self-Paced Workbook

This workbook belongs to:

Date workbook was completed:

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# How to Use this Workbook

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This is your workbook - use it to suit you .... you don't have to read every section just the parts relevant to you. If using a hard copy don't be afraid to write notes on it and use a highlighter. Understand that many topics link and interweave, so moving back and forwards between topics may be helpful.

The workbook is available in both hard copy – available by calling Epilepsy Queensland on 07 3435 5000, and online via the Epilepsy Queensland website.

Footnotes are used throughout to explain terms that may not be commonly understood. You will see a number at the top right hand side of the word and this indicates there is a footnote at the bottom of that page.

Footnote example: Stigma<sup>2</sup>

The clickable links are underlined and written in blue. Press Ctrl + Click and you will be taken to the link. Here's a few sample links:

<https://www.epilepsyqueensland.com.au/>

[Brisbane Community Transport Services](#)

Your feedback and questions are important so we welcome your contact. With different viewpoints and ideas we expect this resource to keep on improving with each update.

## Acknowledgements

Consultation for this project and resource development included a wide range of stakeholders via workshops, interviews, questionnaires and social media groups. Stakeholders included: older people with epilepsy, family members and carers, aged care service providers, neuroscience specialists and more.

This project is proudly funded by a 2019 Access and Inclusion Community Partnership Program grant from Brisbane City Council.

## Who is this workbook intended for and why?

USER GROUP	THE INTENTION
<b>People in later life who have epilepsy</b>	<p>To provide:</p> <ul style="list-style-type: none"><li>• links to resources &amp; services</li><li>• opportunities to improve problem solving and planning</li></ul> <p>Knowledge opens up opportunities. Learning increases your ability to problem solve, communicate and build relationships, to seek support, and potentially to change your approach and maybe your circumstances in order to improve your quality of life.</p>
<b>Family of older people with epilepsy</b>	<p>To provide:</p> <ul style="list-style-type: none"><li>• 'go to' information and resources</li><li>• greater knowledge and understanding of epilepsy in later life along with ways to minimise the challenges</li><li>• opportunities to strengthen personal ability to manage stress and anxiety, to problem solve, communicate and plan</li></ul>
<b>Professionals: Neurologists, doctors and nurses, managers, personal carers, volunteers, people working in community and aged care organisations</b>	<p>While many professionals will have a wealth of epilepsy knowledge and expertise, some may not. This workbook may provide valuable information to support care and practice.</p> <p>Alternatively, health professionals can access "<i>Could it be Epilepsy? A brief guide for health professionals</i>" – available on the Epilepsy Queensland website.</p> <p>Aged care services and other health/community services may also wish to schedule staff training on understanding epilepsy, seizure first aid, as well as the impacts of epilepsy on seniors, with practical strategies to provide support and care. Contact Epilepsy Queensland for more information on training available.</p>

# Introduction

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Epilepsy is a common and serious neurological disorder with more than 50 million people diagnosed worldwide (World Health Organization, 2019). However, the true impact of this condition is far greater, considering the prevalence of un/misdiagnosis and impact on families/carers. This complex condition affects around 100,000 Queenslanders. Records of epilepsy have been found as far back as 2000 BC and in the 5th century BC it was known as 'The Sacred Disease'. It continues to be highly misunderstood and stigmatized.

Diagnosis is highest in children under the age of 5 and adults over the age of 60. Epilepsy is not always the first possibility that comes to mind when an older adult has a seizure. Its clinical presentation can resemble other conditions, such as stroke, head injury, brain tumors, cardiovascular disease, chronic alcoholism, Alzheimer's disease or dementia.

Living with epilepsy may be challenging, with a profound impact on a person's independence and capacity for community engagement, obtaining/retaining a job and social inclusion. For some it has been a long-term condition, while for others it is a diagnosis made later in life. Mix the challenges of epilepsy with those of aging and life can become overwhelming.

Epilepsy Queensland Inc. (EQI), consulted with its members, professional specialists, clinicians and other agencies to better understand the needs of people with epilepsy in later life. Information on the topics raised below are threaded throughout this workbook.

- opportunities to strengthen wellbeing and individual capacity
- a broader consideration of health & wellbeing
- epilepsy and seizure knowledge for self and others-including health and community services
- a need for greater awareness and understanding of epilepsy
- strategies to enhance safety and independence

*The overarching goal of this workbook is, to provide practical ways of achieving the best possible life, given each person's unique circumstances - through the sharing of knowledge, resources, methods, and examples and importantly to give hope and inspiration.*

It is difficult for one resource to meet the needs of every person living with epilepsy and/or other medical conditions, hence, it is emphasized that this workbook does not cover all possible issues, and the potential solutions are suggestions or recommendations and will not necessarily meet every person's unique needs.



# PART 1: EPILEPSY

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## Epilepsy Education

Many people living with epilepsy find it important to learn as much about the condition as possible, and to engage with others with similar experiences. Ideally, the more informed you are, the more confident and capable you will be in dealing with it.

Whether you are a professional or a family member/carer of a person living with epilepsy, knowing as much as possible about epilepsy and the impact it can have on a person's life, will place you in a better position to understand, assist and support others. Hearing the stories of others and imagining yourself in their situation will enable you to increase understanding, to ask the right questions, and display real empathy. None of us can really 'be' in the shoes of anyone else, but the more we try, the better we connect with people.

Epilepsy Queensland offers training and education sessions for people with epilepsy, families/ carers and health/community workers, which includes information on:

- understanding epilepsy
- seizure types and management
- minimizing triggers
- seizure first aid
- strategies to enhance safety, independence and wellbeing

Similarly, Epilepsy Queensland can provide information and referral information; as well as opportunities to connect with others living with epilepsy. For more information contact the Services team on 07 3435 5000.



## PART 2: THE CHALLENGES

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The latter years of life can include many wonderful things: grandchildren; hobbies and interests; travel; gardening; being part of the community; and simply having more freedom and time to do as you please.

Epilepsy Queensland set out to determine the most common issues experienced by older people with epilepsy, issues that limit a person's ability to access the community and enjoy life to the fullest. These were the most common challenges identified:

- Feelings of loss of control
- Emotional issues: fear, anxiety, stress, sadness, reduced self-esteem and confidence
- Accepting and adapting to change
- Seizures: the fear of having seizures in public and the risks at home
- Finding the 'right' medical support. Some people reported long waits between being diagnosed and getting to the 'right' specialist and support as well as gaps in communication between the GP and specialist/s
- Not receiving a referral to Epilepsy Queensland on diagnosis
- Stigma<sup>1</sup>: in the workplace, with the general public, some support agencies/staff and with some family/friends
- Loss of driver's licence & independence, therefore, greater reliance on others.
- Transport issues leading to lowered social and community involvement
- Problem solving and decision-making
- Carers/family – level of availability and support
- Sleep: insufficient quantity and quality.



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<sup>1</sup> Stigma – a social stigma is the negative treatment of, or discrimination against, a person because of a characteristic that sets them apart from other members of a society. With epilepsy many people will have experienced being treated differently, as having low intelligence, or even being restricted from doing things that they are capable of doing. Research shows that a stigma is broken down through education, talking openly, sharing knowledge, and empowerment of those affected.





The effect of the above issues on a person's mental health and general wellbeing, especially the timing of the right support and medication, can vary from person to person.

The longer the struggle, the more it impacts negatively on a person's emotional state and ability to cope. Epilepsy is associated with an increased prevalence of mental health disorders including anxiety, depression and suicidal thoughts. Hence, dealing with problems and emotional issues as quickly as possible is extremely important.

*"And in the end, it's not the years in your life that count. It's the life in your years"*  
- Abraham Lincoln

We have threaded a range of information and tools throughout the workbook, to assist you to identify problems/emotional states, seek opportunities for improvement, and implement change. Our hope is that you will feel more confident and capable in managing the impact of living with epilepsy and this will impact positively on your quality of life.

## PART 3: STRONGER ME, BETTER LIFE

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### Individual Capacity Building

Individual capacity building is about strengthening your capabilities, however, it must be stressed that what we are able to include here is limited. It is recommended you use this as a foundation from which you can explore and work towards personal growth and development on an ongoing basis.

Research has shown that improving a person's individual capacity improves their ability to solve problems, achieve better results for themselves (even in extremely difficult circumstances) and to avoid unnecessary worries. In many instances, it results in a person not being as reliant on others as they may have been.

In the case of epilepsy, some people may always be reliant on another person. They may always need someone with them in some or even all parts of life. Being stronger in other areas though, is likely to help build higher levels of self-esteem, confidence, achievement and happiness.

Books and information are available at libraries and on the Internet. There are many articles and videos to learn from, including educational self-development programs. You may like to search for - 'personal development' or videos from Tony Robbins - an American author, life coach and philanthropist who focuses on personal development.

You might also talk to other people or seek professional coaching or counseling if you feel that is the right thing for you.

### What is Individual Capacity Building?

'Individual capacity building' is the term used to describe the process of educating people and putting them in touch with strengths and resources they weren't aware they had. Its objectives are to strengthen capabilities to:

- adapt to change
- resolve problems
- communicate with purpose, to speak up and advocate for oneself
- set and achieve goals
- be empowered: feel more confident and able to control your own life
- be happy

Read on, to find out how you can increase your personal capacity building.

## PART 3: STRONGER ME, BETTER LIFE

### What Capacity Building Can Mean For You

The Difference	What it might mean for you	Ideas on how to do this...
<b>A greater ability to accept what cannot be changed</b>	<ul style="list-style-type: none"><li>• Reduced stress and anxiety, increased calmness and inner peace</li><li>• Improved mental health</li><li>• A positive difference to physical health (eg blood pressure and immune system).</li><li>• Greater focus on what can be changed, what is wanted and not what isn't wanted</li></ul>	<ul style="list-style-type: none"><li>• Listening to music</li><li>• Walking in the garden</li><li>• Cross words</li><li>• Singing out loud</li><li>• Complete part 3 to learn about the circle of control</li><li>• Mindfulness classes – Mindfulness simply means paying attention to the present moment. Practising mindfulness can help you to cope with everyday life.</li></ul>
<b>Greater ability to make choices and solve your own problems</b>	<ul style="list-style-type: none"><li>• Recognition when an emotion is a signal that you have a problem to solve</li><li>• Avoid or minimize emotional stress</li><li>• A sense of achievement and improved self-esteem</li></ul>	<ul style="list-style-type: none"><li>• Gather information in a way that is right for you – do you need it written down, explained to you etc. This will help you make informed decisions and weigh up the options</li><li>• What can you learn from previous experiences?</li></ul>
<b>Communicate with purpose, speaking up and advocate for yourself</b>	<ul style="list-style-type: none"><li>• Relationships benefit: with your spouse/ family carers and all sorts of people</li><li>• Effective communication means you are better equipped to ask the right questions at medical and other appointments on the phone or face to face</li><li>• Confusion and conflict can be avoided or managed more effectively</li><li>• Having confidence equips a person to make new friends, to discuss epilepsy and your circumstances</li></ul>	<ul style="list-style-type: none"><li>• Seek out the support of family/ friends as needed</li><li>• Practice talking with others and speaking your mind confidently</li><li>• Practice how to use communication tools (part 4)</li></ul>



## PART 3: STRONGER ME, BETTER LIFE

### What Capacity Building Can Mean For You

The Difference	What it might mean for you	Ideas on how to do this...
<b>Achieving goals</b>	<ul style="list-style-type: none"> <li>• Greater purpose and improvement in the areas in life that are lacking</li> <li>• Goals provide focus on the positives and motivation for action,</li> <li>• Goals provide opportunities for celebration</li> <li>• Helps build a healthy self-esteem</li> </ul>	<ul style="list-style-type: none"> <li>• Refer to part 4 for ideas on how to develop and achieve personal goals</li> </ul> <p><i>A <b>DREAM</b> written down with a date becomes a goal.</i>  <i>A <b>GOAL</b> broken down into steps becomes a plan.</i>  <i>A <b>PLAN</b> backed by action becomes a <b>REALITY</b>.</i></p>
<b>Be empowered, feel more confident</b>	<ul style="list-style-type: none"> <li>• Improved self-esteem</li> <li>• No longer be embarrassed or apologize because of a seizure</li> <li>• A healthy relationship with yourself sets the foundation for healthy relationships with others.</li> <li>• You are more likely to recognize when your behaviour is effected by emotions and so manage them better</li> <li>• Managing emotions helps with motivation and achievement of goals, it leads to greater inner peace</li> <li>• More emotional awareness means more recognition of emotions in other people which leads to better communication and better relationships</li> </ul>	<ul style="list-style-type: none"> <li>• Recognise that it is okay to be different. All people have strengths and weaknesses .... areas for growth</li> <li>• The more aware you are of who you are and why, and what you believe, the more empowered you will be. The info and examples in this book will help you.</li> <li>• Help break down the stigma of epilepsy – can you undertake fundraising or awareness raising activities; peer support activities etc.?</li> </ul>
<b>Being happy</b>	<ul style="list-style-type: none"> <li>• In spite of aging and having epilepsy and other health issues, appreciating what you can do and focusing on what you can be grateful for fills your mind more with positivity and enables you to focus on happiness</li> <li>• Life is not perfect. It is how we respond to what we are presented with that really makes the difference</li> </ul>	<p><i>It is how you respond to the events of life's journey that makes the difference to your results.</i></p> <p><i>Do you choose to walk the same path and stay in your comfort zone, even if it is uncomfortable?</i></p> <p><i>Or do you crush the leaves beneath your feet and step into the beginnings of a new path?</i></p>





## Have you tried this breathing exercise before?

It will help you to slow down and focus on the current moment.  
This may be helpful in times of stress or anxiety.

Notice the following around you:



5 things you can see



2 things you can smell



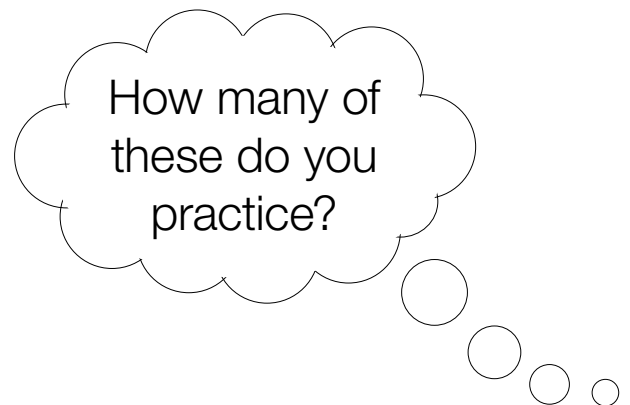
4 things you can feel



1 thing you can taste



3 things you can hear



## 10 ways to be happy!



Meditate

Spend Time with Family



Plan a trip

Move Closer to Work



Practice Gratitude

Go Outside



Help Others

Sleep More



Practice Smiling

Exercise



## PART 3: STRONGER ME, BETTER LIFE

### Values and Beliefs

The sort of person we are and the actions and behaviour we display are driven by our values and beliefs. What you have valued the most and what you have believed are the things that have driven your thinking and behavior. Like a map or GPS guides you to a location, your values and beliefs have driven you to make all the decisions and choices that have taken you from one point in your life's journey to be who you are and where you are now.

Knowing and understanding your values and beliefs is extremely useful. Someone who has been diagnosed with epilepsy may not have realized that they valued independence so highly, but now having lost their driver's licence and having to rely on other people, they find that independence is something they value highly. Reviewing values and beliefs is one part of a process to help them adjust and gain inner peace.

#### A BELIEF

is an internal feeling that something is true, even though there may be no evidence to uphold it and even if that belief is wrong or not helpful.  
*I believe happiness is more important than money.*

#### A VALUE

is a measure of worth or importance attached to something. Values often reflect the way we live our life.  
*I value honesty, freedom of speech, and my family..*

#### ATTITUDE

is the way a person expresses or applies their beliefs and values. Attitude is seen in how a person communicates and behaves.  
*I can't be bothered.... I hate sport.....*

### Beliefs that Help and Hinder

Beliefs develop as a result of the influence of culture, religion, family and upbringing, key people in your life, personal and other events, media influences, what you read and learn, and all the pieces of 'evidence' gathered from experiences and observation. Beliefs can change slowly over time, or suddenly, often from traumatic experiences or when evidence accumulated overflows and bursts into an 'aha moment' – a striking realization.

Before being diagnosed with epilepsy a person may have believed that they had a tough life but then with a diagnosis of epilepsy they now believe that life before was easier than they realized - they didn't know how good they had it. People who have positive beliefs are more likely to get the most out of their life even with aging and epilepsy.

***The trick is in reframing our thinking  
- and this takes practice!***

## PART 3: STRONGER ME, BETTER LIFE

### Values and Beliefs

#### Beliefs that Help and Hinder

Old Belief	New Belief	What Changed The Belief
Life is hard	Life before was pretty easy	<ul style="list-style-type: none"><li>• Diagnosis of Epilepsy</li></ul>
Epilepsy means I can't do...	I can be happy	<ul style="list-style-type: none"><li>• Meeting other people who have epilepsy, hearing their stories, learning how people have adapted and managed to get the most out of their life has changed the previous beliefs held</li><li>• Learning to manage my emotions for better results</li><li>• Improving my communication skills so my questioning is more specific</li></ul>
These are the 'cards' in life I have been dealt, there is nothing I can do about it	I can do something, I can improve my situation	<ul style="list-style-type: none"><li>• Learning about other people who have experienced extremely difficult challenges and have managed to find purpose in life</li><li>• Taking on a new attitude and problem solving</li><li>• Changing habits to thinking positively and setting goals</li></ul>



Are there others that you can think of?:

Old Belief	New Belief	What Changed The Belief

## PART 3: STRONGER ME, BETTER LIFE

### Values and Beliefs

#### What Do You Value the Most?

Our values are the things that are most important to us, they are the foundation of who we are and how we live and work. Our values determine our priorities. If a person's actions or achievements don't agree with their values, then they are more likely to be discontented. Values can impact on relationships. In the case of a couple, a group of friends or even an employee working for a business, if the same or similar values are held, the relationship is going to have a greater chance of success.

Values are a very personal thing so there is no right or wrong as far as what you identify as your values. Here is a sample:



It is not uncommon when people have experienced a personal tragedy or near death experience, or even if they take time to think deeply about what they value the most, that they find their highest values to be things such as love, health, family and relationships and not the material things that they had been working so very hard to acquire.

When you take time to review what you value the most and what beliefs you hold around those values, ask yourself how you came to have them. Question whether they still apply. You might find that some are no longer relevant or helpful. You might find that with the passing of time, your beliefs no longer align with your changed situation, with who you are now. Health might be one of your high values and you have a belief that you are fairly fit and healthy or alternatively you might not have valued health and realize now that you need to.



## PART 3: STRONGER ME, BETTER LIFE

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### Wheel of Life

#### Wheel of Life – a tool to identify ‘where you are’ in life now

Whenever a person sets out to do a job or project, large or small, there is always a starting point and an ending. If you were creating a vegie garden, building a house, or planning Christmas you always have a starting point (this is what I have now) and an idea and vision (this is what I want in the end). Even if you haven't thought of it in this way, the end result is a goal. If you don't believe the end result to be possible, then it's really just a dream. So assessing the current situation is the first step. A 'Wheel of Life' is a great tool to determine 'where you are' in life now.

The 'Wheel of Life' is a self-evaluation tool commonly used in coaching and counseling to help people see where they are doing well and where they are not doing so well: what areas, if improved or strengthened will help get the results they need and want. It identifies where greater focus is required in order to achieve greater quality of life.



## PART 3: STRONGER ME, BETTER LIFE

### Wheel of Life

#### Wheel of Life – a tool to identify ‘where you are’ in life now

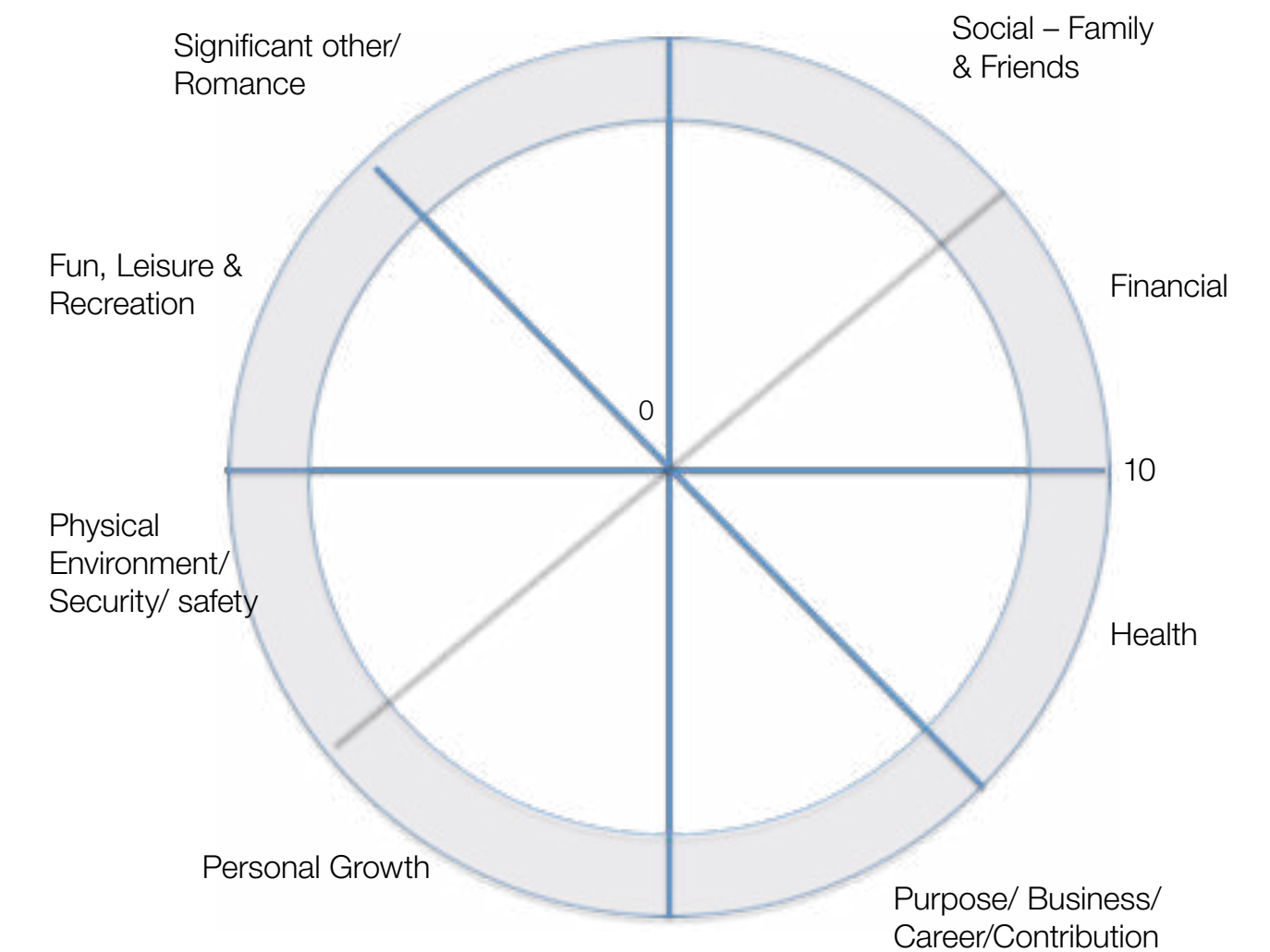
Questions to assist in determining your evaluation for each segment of the Wheel.

Whole of Life Potential Segment Labels	Sample Questions to Help with Evaluation
Emotional wellness (Eg: anger, fear, self esteem & confidence, negativity)	<ul style="list-style-type: none"> <li>• How much of my time do I experience negative emotions?</li> <li>• Do negative emotions linger too long?</li> <li>• How satisfied am I with my skills to deal with my emotions?</li> <li>• Does my emotional state stop me from doing the things I want to do?</li> <li>• To what level do I feel inner peace?</li> <li>• How much do I feel love and love others in return?</li> <li>• Do I have a good level of laughter and fun in my life?</li> <li>• Am I enjoying life, do I smile?</li> </ul>
Physical health & fitness; including food and diet	<ul style="list-style-type: none"> <li>• Have I sufficient energy to do all that I have to do with some energy left over for fun and recreation?</li> <li>• What amount of focus do I give to my health and fitness?</li> <li>• Do I eat a good variety of fruit and vegetables?</li> <li>• Do I understand the link between what I eat and how my body responds or how I feel?</li> <li>• Do I eat for the sake of eating, when I am not truly hungry?</li> </ul>
Finances	<ul style="list-style-type: none"> <li>• Have I sufficient income to meet my expenses with some left over for fun or savings?</li> <li>• How much do I understand my financial situation?</li> <li>• Do I review my finances frequently enough?</li> </ul>
Home & Physical Environment	<ul style="list-style-type: none"> <li>• To what degree do I feel safe and comfortable in and around my home?</li> <li>• Do I appreciate what there is to be grateful for where I live?</li> </ul>
Business, Career & Purpose	<ul style="list-style-type: none"> <li>• How would I rate the success of my business or career?</li> <li>• If I no longer have a career or business, then how satisfied am I that I have a purpose in life? Do I get a sense of achievement from things I do, from goals for myself?</li> </ul>
Personal growth	<ul style="list-style-type: none"> <li>• Have I stopped bothering with learning and developing myself?</li> <li>• Do I adapt well to the changes in my circumstances and environment?</li> </ul>
Marriage /Romance	<ul style="list-style-type: none"> <li>• Do I have a loving relationship? Is there room for improvement?</li> <li>• Do we understand, empathise and support each other?</li> </ul>
Family and friends	<ul style="list-style-type: none"> <li>• How satisfied am I with the friends I have and the quality of the friendships?</li> <li>• Do I have friends that I could count on?</li> <li>• Do I have things in common with my friends?</li> <li>• How often do I talk or meet up with my friends?</li> <li>• Do my friends listen to me and do I listen to them ... with a purpose of really valuing each other?</li> </ul>

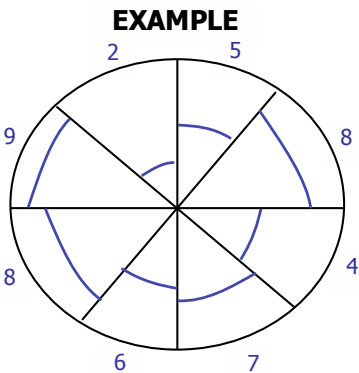
# PART 3: STRONGER ME, BETTER LIFE

## Instructions

- If you wish, change the category names to ensure they reflect each important area of your life
- Record the date and the colour pen you use
- Using a scale of 0 (the worst rating) in the centre of the wheel to 10 (the best rating) on the outside of the wheel, draw a line across each category indicating your level of satisfaction/dissatisfaction
- On the back of the sheet write out the actions that you will take to improve the areas rated as low (For example: fun, leisure & recreation : Actions - join a kayaking club, allocate every 2nd Sunday for family outings; increase fun at work and spontaneity at home; pay to have lawns mowed so I can increase leisure time)
- Complete the wheel at different intervals using different coloured pens, to check progress



Date:	/	/	Colour used:	.....
Date:	/	/	Colour used:	.....
Date:	/	/	Colour used:	.....



## PART 3: STRONGER ME, BETTER LIFE

### Wheel of Life

#### Wheel of Life – a tool to identify ‘where you are’ in life now

The wheel can also be copied and used specifically to focus on one topic, such as health or financial literacy. Simply break down the topic into smaller sub sections. For example, health may be broken down into - exercise, diet, medication (side effects/adherence), mental health etc.

When you have completed the wheel you will see where you have scored well and where you have scored lower. If there are imbalances (a wobbly wheel!), it means that the areas with low ratings will benefit from greater focus and action.

The question now is ‘how can you bring those lower scores out towards the rating of 10 to end up with a well balanced wheel and better life?’. It’s important also to ensure that as you make these plans and changes that you don’t do it at the expense of an area that is performing well.

The idea is to strive for a well-balanced life, so **BALANCING** your focus is the key.

Based on the results above, please consider....

#### To enhance my quality of life...

What do I need to do more of?	What do I need to do less of?	What is working well and needs no change at this time?



## PART 3: STRONGER ME, BETTER LIFE

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### Wheel of Life

#### How Values and Beliefs Impact on Our Behaviour (a fictional scenario)

*Margie was happily married with three adult children and 5 grandchildren. She had always been a highly independent woman successfully managing the family home and the upbringing of her children while simultaneously achieving a rather successful career. She retired at the age of 65 and was really enjoying life..... until at 67 she was diagnosed epilepsy.*

*One of Margie's highest values was independence. Independence is the freedom to be in control, to make your own decisions, free of support and without an essential need of help from others. It is a skill, a competency and although she did not realize it, independence was a strong building block in Margie's self-esteem.*

Margie had been brought up to be independent, it was part of who she was and it had enabled her to cope with all sorts of challenges throughout life. When Margie retired she had maintained her independence: driving her own car, playing tennis, planning holidays, coffee with friends, and spending greater amounts of quality time with her husband. She made her own decisions, was an equal partner in their marriage and was assertive when she needed to be.

When Margie was diagnosed with epilepsy she was no longer able to drive and she had to have someone with her almost all the time. Margie experienced feelings of anger, loss and sadness, and her self-esteem and confidence was knocked severely.

The high valuing of 'independence' was upheld by Margie's beliefs that:

- Independence was an essential part of who she was
- People who weren't independent were burdens

Margie struggled with her situation for a long while until, with some counseling, she grew to accept that if she continued to hold onto 'the Margie of before', she would continue to feel a burden on other people, to feel stress, loss, sadness and her self-esteem would continue to plummet.

Margie began to realise that we all have change thrust upon us throughout life. She remembered having been made redundant from a job she loved, she remembered finding out she was pregnant when they hadn't planned it, and she remembered plenty of things that she adapted to and how she learned from those experiences. She had been quite a strong person. Margie decided it was time! Time to accept a change that she had no control over and to let go of the Margie of before. She knew that now she had to focus on what she could control or at least influence.

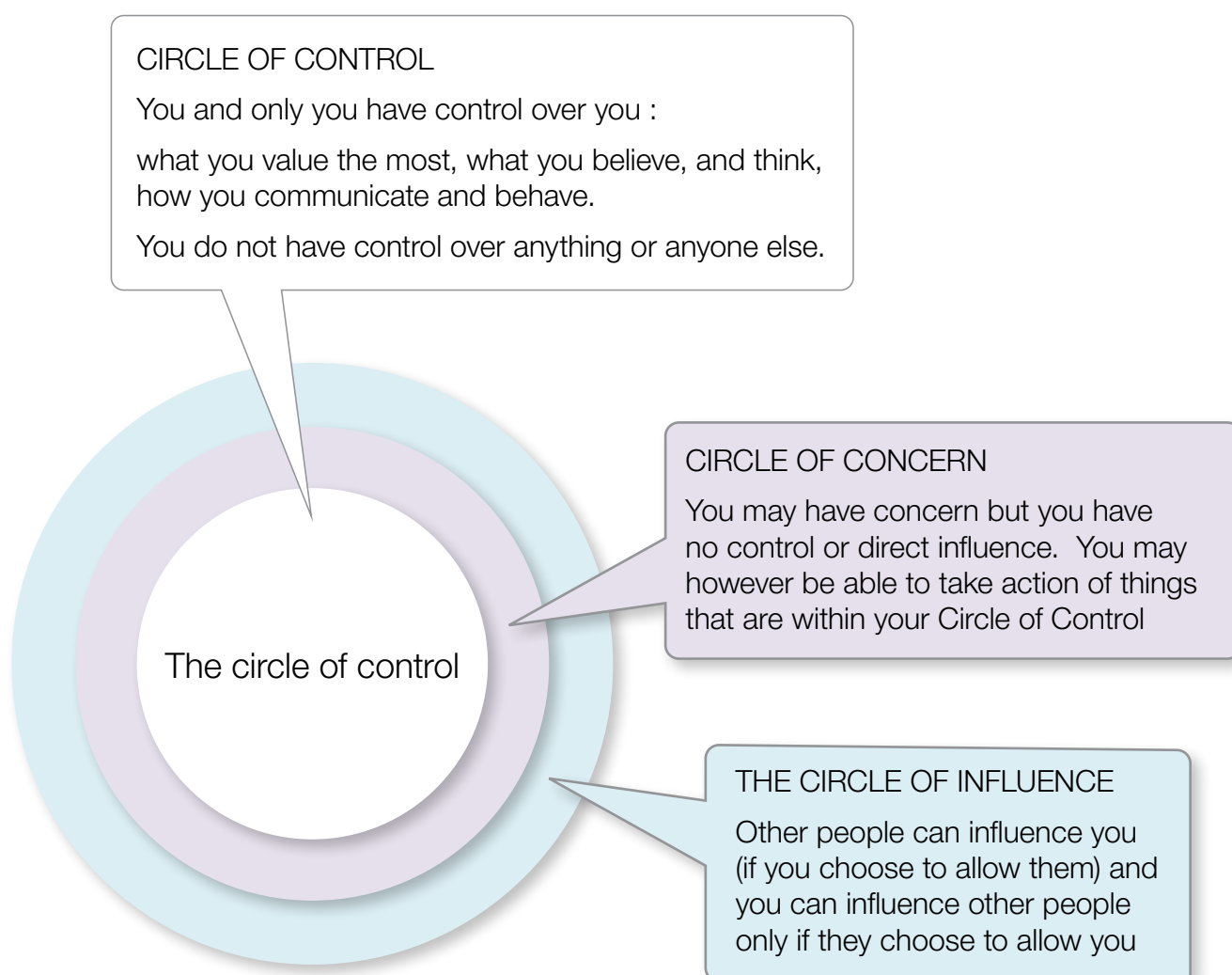
*A person's behaviour is a symptom of what is going on inside of them.  
Explore what it is that is going on inside you (or your loved one)  
Getting to the specifics is the way to problem solving.*

## PART 3: STRONGER ME, BETTER LIFE

### Control & Influence

There are things that are outside our control that we need to accept but there are things that we can control and influence in order to get better results for ourselves. Only one person controls you and this person is you. We can influence other people with our attitudes and by what we say and do. In turn, other people can influence us with their words, attitudes and behaviours, but no-one actually controls another person's thinking or behaviour.

We are each the 'driver' of our own thinking and behaviour. So when you hear someone say 'oh he made me so angry or so upset', in reality, feeling angry or upset was what they allowed themselves to be as a result of the other person's influence. Anger, fear, and other emotions cannot be felt by your hands, they are created in your mind. A person responds to another's behaviour with the emotional response of anger, largely because they do not know how to respond differently or manage their own emotions.



## PART 3: STRONGER ME, BETTER LIFE

### Control & Influence

#### Control versus Influence - points to note:

- In spite of all the events and influences a person has experienced, it is their choices, decisions and responses that have brought them to where they are now. Choices and decisions we make today and in the future will lead us to our future destination
- People who spend larger amounts of time in the Circle of Control will see results
- People who wish to achieve better results understand that if the relationship and results they are getting is not what they want, then the only thing they can do is to change their thinking and behaviour to better influence the other people
- People who spend large amounts of time in the Circle of Concern will not see results for their time and energy
- Reactive people – waste much time and energy on issues that they do not have control over
- People find that it easier to 'let go' when they understand that there is nothing they can do and so acceptance is the best measure for improved mental health and wellbeing



#### EPILEPSY SPOTLIGHT

If you want to achieve and adapt to change successfully then take these steps:

- Spend a greater percentage of your time focusing on and increasing things in your circle of control
- No person has control over the past or future, so take control over what you can now
- Ask what will happen if I continue to spend more time on things I have no control or influence over?
- Ask what will I achieve if I devote more time and energy to things within my circle of control?

People whose focus is largely on the concern area believe they have little or no control or influence over certain situations. They have a tendency to blame other people and circumstances for their situation.

*When a person recognizes where/what they have no control over and dedicate a greater percentage of their time and energy to what IS within their control - they are more likely to become more effective and achieve more of what they want out of life.*

## PART 3: STRONGER ME, BETTER LIFE

Consider these examples...

Things in your control	Things you might be able to influence	Things you have no influence over
<ul style="list-style-type: none"><li>• What you think and do</li><li>• What you value the most</li><li>• What sort of person you choose to be</li><li>• How you spend your time</li><li>• How you respond to others even in difficult situations or in conflict</li><li>• Whether you do yoga or meditate</li><li>• Whether you exercise</li><li>• Who you have as friends</li><li>• How much time you dedicate to sleeping</li><li>• How you manage your emotions</li><li>• What you believe</li><li>• Whether you do good things for other people</li><li>• The type of self-talk you engage in (positive &amp; beneficial, negative, self-criticism)</li><li>• Habits you develop and maintain</li></ul>	<ul style="list-style-type: none"><li>• How others respond to you</li><li>• Opinions of others</li><li>• Other people's choices and actions</li><li>• What other people understand about epilepsy</li><li>• Bodily changes in yourself (can't stop aging but you can actively seek to influence your health &amp; fitness)</li><li>• Pain – you may be able to influence how it is handled</li><li>• Other people's self-esteem &amp; confidence can be influenced by what you say</li><li>• You might have influenced in the environment and politics if you are actively engaged</li></ul>	<ul style="list-style-type: none"><li>• The past – past mistakes, accidents, illnesses</li><li>• Your heritage, genetics, childhood and family</li><li>• Other people's beliefs, opinions, behaviours and what they say</li><li>• The news</li><li>• The weather</li><li>• Wars and conflict in the world</li><li>• Traffic conditions</li><li>• Change in your environment and the world around you</li><li>• Unknowns of the future</li><li>• Fairness – life is not always fair</li><li>• Being in control – no-one is in control of everything or anyone else</li></ul>



# PART 3: STRONGER ME, BETTER LIFE

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Are there others that you consider important to you?

Things in your control	Things you might be able to influence	Things you have no influence over

## PART 3: STRONGER ME, BETTER LIFE

### Control & Influence

#### Hints to Increase Your Influence

- Value other people's opinions and input and listen with a purpose of truly understanding
- Be specific, ask for specific details (when, where, why, how, who) in your preferred communication style
- Dedicate full attention to the person who is speaking and if for any reason you can't, then let them know, defer the conversation, ask for it in writing
- Use the best method of communication to get results: face to face, letter, phone, email

- ☐ Manage your emotions: understand that emotions you may want to show at any moment may not get the results you really want. Think about what emotion you need to display, think about what will happen if you retaliate.
- ☐ Know that how your behaviour emotionally is learned.
- ☐ Where did you learn how to manage anger, affection, love, fear and sadness? Is this way of managing it beneficial?
- ☐ Observe how others communicate with you, how do you feel when they are truly listening, truly empathetic?

- How helpful is blame? Don't just be 50% responsible for the communication and if you want the right results then take on 100% ownership.
- Be flexible: The more flexible and adaptable a person (or any system) the more successful - in a wide range of situations with a wide range of people
- Silence is a powerful tool
- Being right all the time is not realistic. What is the purpose? Letting go of these feelings, even when you feel right, leads to better relationships.

- ☐ Weigh up what is worth arguing for, it doesn't always matter
- ☐ Be assertive when you need to be remembering that assertiveness is not aggressiveness but being confident and brave enough to speak your mind

## PART 3: STRONGER ME, BETTER LIFE

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### Control & Influence

#### Hints for Letting Go...

Letting go is hard because hanging on is based on fear – fear of the unknown, the ‘what if’s’?. Letting go is acknowledging that you are entering different territory, you are bidding farewell perhaps to who you were, how you were, how your life was, and the expectations you had in the past for the future.

- ☐ Gather the evidence – ask what if I don’t? what if I do? Compare the negatives versus the positives, the pain versus the possibilities of greater pleasure
- ☐ Think about past experiences where you have hung on to something painful? Did you move on? Do you still believe the same and feel the same?
- ☐ Think about the past experiences - where you did let go? Was it a relief? How did it feel in the end?
- ☐ How it will be for you in a year or five years time if you don’t let go
- ☐ Think about past challenges you have had and the courage and determination that you mustered up
- ☐ Reinforce to yourself that this is something in your control, something difficult for sure but something that you have a choice about
- ☐ Can you visualise the difference?
- ☐ If you feel as though you are not ready to ‘let go’ then ask yourself ‘when will I be ready’, what deadline can I give myself .... tomorrow, next week or at 5pm today?

*Hanging on and not letting go becomes a habit  
It is often a case of hanging on to what you know, even if it is painful  
Habits are learned behaviour  
What is learned can be unlearned*

Is there anything I feel I need to ‘let go’ at this time?

## PART 3: STRONGER ME, BETTER LIFE

### Focus

Having read about control versus influence it's time to learn how to focus more of your time on the things within your control, instead of things outside your control or that you have little or no influence over.

**You can improve your life just by changing your focus!**

**The more you focus on something, the better you become at doing it**

**The more you focus on worry and stress, the better you become at doing it**

If a person has a passion to become a famous tennis player, then they practice and play tennis, they think about it 'all' the time, they talk about it much of the time, they develop strength in all the right muscles until they become a better and better tennis player. Their focus is on being a great tennis player. The more a person focuses on one thing the better they become at that one thing. The more we rehearse and focus on a certain thing, such as having a positive mindset, the stronger our neural circuitry becomes in regard to that.



### EPILEPSY SPOTLIGHT

When you become more self-aware, more in control of your thoughts, you can acknowledge those thoughts of fear and embarrassment at having had a seizure in public. You can push them away, 'unfriend' them as you would someone on Facebook.

Then grab the new positive thoughts, that say ***'it's okay, I have nothing to be embarrassed about, I don't need to feel embarrassed. It's their lack of knowledge and understanding and anyway I don't know what other people are thinking.'*** Focus on what you want and strengthen the positive rewiring in your brain.

It may also be a great teaching moment to increase the understanding and awareness of epilepsy.

**Have you ever noticed that when you have a problem, your mind can seem totally absorbed with it, absolutely filled and overflowing with that problem? Even an exciting thing like buying a car or planning a party – everything takes up all the space in your mind.**

If it is a negative problem, it's often followed by lots of other negative things. When we experience negative issues our brain might be filled with negativity, and it is easy for our focus to be negative allowing very little 'space' or clarity to think about other things in our life.

## PART 3: STRONGER ME, BETTER LIFE

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### Focus

#### Your Brain as a Jug

Imagine the brain as a jug, with muddy water, not quite full but almost. Cloudy murky water that looks dirty, feels gritty and smells bad too! There's not much room left for clear water. But, you start pouring lovely clean fresh crystal clear water into the jug, a bit at a time. You eventually fill up the jug and the muddy water is still very muddy - but not quite as muddy as it was before. You keep pouring in that lovely clean fresh crystal clear water so that the jug is now overflowing. Thankfully you have chosen to do this outside! You keep pouring and as you do, the water in the jug becomes clearer and clearer and clearer until eventually the jug of water is very clear. There might be a bit of murky sludge at the bottom, but basically, the water in the jug is clear.

Now imagine that if this jug is your brain, the muddy water represents all the negative thinking, worry, anxiety and stress. It has come about because your focus is not balanced well, your focus is largely on all the negatives and so it is very understandable that your thinking and decision-making, and your ability to solve problems, or even recognize them in the first place, has been clouded too.

Now imagine pouring into that clouded brain, loads of good things – the things you can be grateful for, the things that you have in your life that you consider to be good or positive things to look forward to in the future. Your brain will clear, your emotional state will change for the better. The problem still remains, but your brain is now in a better state to tackle problem-solving and you will find yourself switching the negative emotions towards more positive emotions.





## PART 3: STRONGER ME, BETTER LIFE

### Focus

#### Helping Your 'jug' Become Clearer

- ☐ Focus on what IS achievable and what is in your control
- ☐ Write a list or think of all the things you have to be grateful for:
- ☐ If you struggle to find things in your life to be grateful for here's some suggestions:



Family and friends

The roof over your head

Aspects of your health that are good

The food and clothing you have

The good experiences you've had

Living in a free country



Being able to read and to learn

The sun, the moon, the stars, the sky

Your pet and the joy it brings

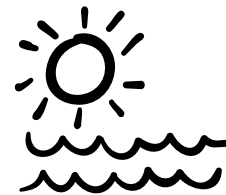
Having television and the internet

Being able to cook or garden



Things that you CAN do

Feeling the sensation of being happy



#### Practicing Gratitude – what are you grateful for in your life?

## PART 4: GOALS AND ACHIEVEMENT

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If a person doesn't believe something is possible, then it is only a dream. However, if you have a dream that is also a goal then that is different!

That is how champions become champions, how explorers discovered new lands across unknown seas and how people like Oscar Wilde, J.R. Tolkien, Stephen King and J.K. Rowling, all pushed through challenges to complete so many amazing written works.

All of these people probably experienced self-doubt at different times, but with focus on the end results, with self-discipline, with moving away from fear and towards their reward, and being persistent - they chipped away bit by bit and got there! They did not allow the fear of such huge goals to rule their lives. They took one step, then another, then another. Your goals may not seem as amazing as these, but in your circumstances perhaps they are. Discovering a better way of life for you will be as great as discovering new lands was for an explorer.

Criteria for goals:

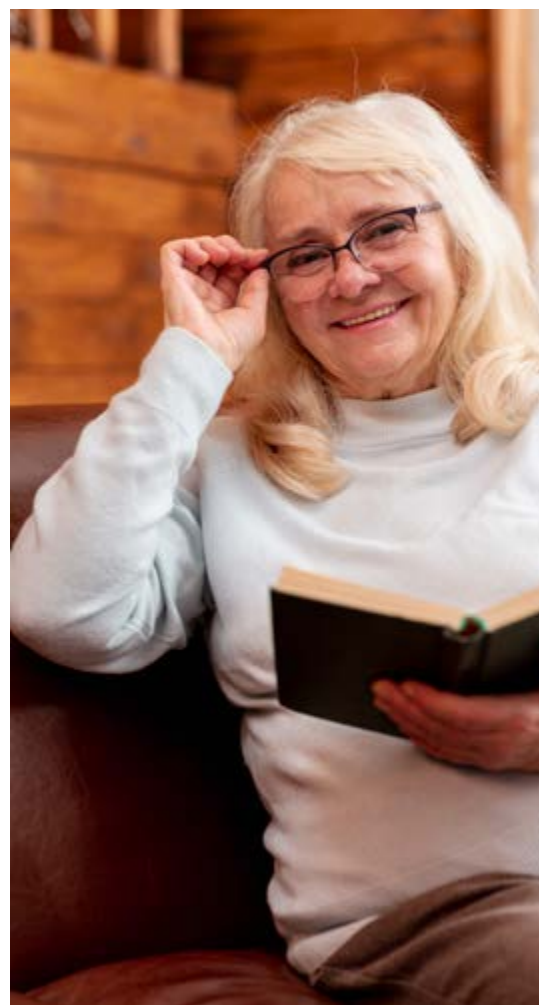
- ✓ Believed to be achievable
- ✓ There are benefits and rewards for getting it
- ✓ There is a level of motivation to achieve it
- ✓ You can visualize having it
- ✓ You have set a date for achievement

### The Goal Tool Shed

S.M.A.R.T. is an acronym widely used in goal setting. Many people who have overcome challenges and achieved, even in the case of having epilepsy, have set themselves goals and planned how they will achieve the goals.

- |   |   |
|---|---|
| S | Specifically and in simple terms - what is it that I want to achieve?   |
| M | Measureable and meaningful – how will I know when it has been achieved? Will it be a simple yes or no, will the measure be something like a weight loss of 8kg? |
| A | Achievable and imagine having it now (visualization)  |
| R | Realistic and Responsible – is it a realistic goal and am I the one who is responsible for achieving it   |
| T | Time based and Towards what I want  |

From there break it down into actions. Reading a huge thick book can be broken down into reading a chapter a day or then one page at a time. This helps eliminate feelings of feeling overwhelmed. With each part, add comments stating what tasks you will need to do to achieve it.



## PART 4: GOALS AND ACHIEVEMENT

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### Here's a sample:

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Overarching goal	Lose 8 kilogram by 30th June 2020 and fit into my size 14 black slacks
Sub-goals	<ul style="list-style-type: none"><li>• Lose 0.8 kilogram per week over a ten-week period</li><li>• Complete minimum exercise of 30 minutes x 5 days every week</li><li>• Drink 2.5 litres of water each day</li></ul>
Mini goals	<ul style="list-style-type: none"><li>• Find and cook 3 healthy recipes by 8pm Sunday every week</li><li>• Prepare weekly menu by 8pm every Wednesday</li><li>• Do shopping by 5pm every Friday to support the menu plan</li><li>• Develop habits out of goals and supportive tasks</li></ul>
Supportive tasks	<ul style="list-style-type: none"><li>• Add filling my water bottles to the existing habit of cleaning my teeth each morning;</li><li>• Make visible the healthy recipe book by placing it on the coffee table</li><li>• At morning &amp; afternoon breaks look for healthy recipes</li><li>• If eating out, think ahead about what healthy options I will choose</li><li>• Photocopy blank menu plans and shopping lists</li><li>• Investigate online grocery shopping</li></ul>

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**Tip:** *Linking a new habit to an existing habit is an easy way to commence*

# PART 4: GOALS AND ACHIEVEMENT

A plan improves the chances of success especially if it is in writing and referred to on a regular basis. The plan can be adapted from time to time to overcome any unexpected hurdles or changes. Below is a sample Action Plan to give you an understanding and something to work with.

Why	What	When	Where	How	With Whom
To feel healthy	Walking	Every Tue & Wed – 8am, first thing in the morning	Up to the park and around the oval x 2 times; walking around the house, shopping centre	Slow pace to start with, increasing distance each week.	My dog & two neighbours
To improve my confidence					
To fit into my old clothes	Drink 2.5 litres of water	Daily	At home & while out	Fill water bottle each morning & refill at lunchtime	Self
To have the fitness to join sports or keep up with others	Eat 3 pieces of fruit	Daily	Breakfast at home & take a piece of fruit when out	Buy a selection of fruit each week	Encourage family as well

Questions to ask yourself:

- What will my beliefs and attitude be in achieving these goals?
- What barriers might I have to jump, crash through or go around? Will anything stop me?
- Are there any other resources (people or things) that might help?
- Are there any contingency plans I could have?
- How will I feel and what benefits will I experience when I have achieved it?



## PART 4: GOALS AND ACHIEVEMENT

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### Visualization

Visualization<sup>3</sup> is a powerful tool used often without us even realizing. Our brain uses visualization all the time: Where did I leave my keys, my wallet, my glasses? What will this cake look like when I've finished it?

**Without us even realizing it, our brain grasps an image from our vast bank of memories just for fleeting moments before we think and speak and do the things we do. It isn't just about visual images either.**

We 'hear' the sounds of our children's laughter, we 'hear' the sound of birds or the waves crashing and we can 'feel' the feel of a feather being brushed over our skin or 'smell' the lavender that grew along the path at our nan's place. When we incorporate as many senses as possible, the visualization, the picture, and the memory of it will be even stronger. It will become easier to recall and so more beneficial to us.

**Visualization is a tool used by therapists, sporting coaches and champions achieving all sorts of things. It is used to combat anxiety and fear of all types, by actors rehearsing a role and manage stage fright, by people planning a holiday or an event, by teachers to explain a concept, and even by people locked away in prison - imagining what they will do when they get out!**

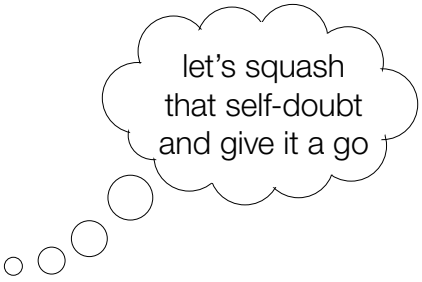
Test your visualization with the exercises below.

Setting the scene:

- ☐ Find a quiet place with a comfy chair, couch or bed, where you won't be disturbed
- ☐ Take calm slow deep breaths as you start
- ☐ Closing your eyes will help focus and eliminate distractions
- ☐ Don't expect the pictures or senses to be perfect, they may just be vague

Exercise One:

- Can you see an elephant?
- Now imagine that elephant is coloured purple
- Put white stripes on that purple elephant



let's squash  
that self-doubt  
and give it a go

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***Tip: It is understandable that some people might think they can't do this or that they won't be any good at it - but once you become more aware of how often you have used vizualisation in the past without realising, and then you practice, you will become more and more of an expert.***

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***Tip: There are many vizualisation videos and exercises on the internet. Just search and you will find them. Your local library may also have books and CDs available too.***

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<sup>3</sup> Visualisation: creating a mental image in your mind of something for example a serene valley of lush green fields, with daisies and cows grazing.



## PART 4: GOALS AND ACHIEVEMENT

### Visualization

#### Exercise Two:

- Select one of your goals
- Make sure you are clear on all the steps you need to take to get it
- Visualise actually being the way you need to be to complete those steps (in the right mood, attitude, feeling powerful)
- Imagine having that goal (actually being that way, doing that thing or having it). Form a picture in your mind and use as many of your senses as possible
- Now fully immerse yourself in the image: see it, hear what you or others are saying, feel it.

After you have done Exercise Two think about how you felt. Did you feel any bodily responses, was your heart beating faster and harder, did your breathing change at all?



#### EPILEPSY SPOTLIGHT



Here are a few example scenarios of how visualisation may help specifically in relation to having epilepsy:

- You've had to surrender your driver's licence - so visualising and rehearsing in your mind the actions of getting a public bus or train and going somewhere or feeling confident about it. Visualising that you are feeling calm and confident, in fact even a bit excited.
- Meeting new people, attending a specialist appointment, asking questions and being confident and sufficiently assertive: visualise and imagine smiling, putting your hand out and shaking hands, and asking questions, being confident and asking even more questions if you need more clarity (...so exactly how did you do that, would you mind explaining that in a different way). **Now imagine how you feel afterwards;**
- Increasing your self-esteem: First, get it clear as to what it is that you want to change about yourself, what you want to achieve and for motivation purposes, what will that do for you? See how you would 'be', visualise actually 'being' the person you want to be, truly feeling those feelings and use as many of your senses as possible feeling what it is like when you are confident and at ease doing something.

Remember visualization and imagining are basically tools of the trade for all sorts of successful people. As you practice visualization it is strengthening the neural pathways in your brain, you are focusing on what you want and not what you don't want and what you want is becoming stronger and stronger.

## PART 4: GOALS AND ACHIEVEMENT

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### Vision Boards

A **Vision Board** is one way to help reinforce the visualization in your mind of your goals. This is a fun way of putting together what it is you want, something for you to reinforce to your brain over and over again helping you to focus not on what you don't want - but what you DO want.

**Here are the simple steps you can take to create your own Vision Board:**

1. Find yourself a wall, a door or board of some sort that you can stick or pin pictures and things to
2. Consider whether you want to keep it private or have it where other people can see it
3. Be prepared to be as creative as you've ever been .... yes everyone has a creative side to them, even you! Colours? Images? Motivational sayings? Photos?
4. Use the Wheel of Life and Goal and Action Plans that you have created to drive what you are going to put on your Vision Board. Really 'own' it
5. Make sure that all the words and pictures you use are simple, positive and 'move' towards your goals - short phrases or single words such as 'thinking', 'choices', 'proactive' and 'self- awareness', and 'be it!'. **Use images that inspire you!**
6. Somewhere on your board it is recommended that you place a section to reinforce that YOU are in control of YOU!
7. Ensure that all the items on your Vision Board are things that you can achieve personally or with some help from a reliable supportive person.



#### DO'S

- ☐ DO look at it each day - look at it intently and not just a glance
- ☐ AS you look at it imagine you have achieved it now, and notice the feelings you get with each part of the Vision Board
- ☐ MAKE it a regular habit to ask what, if anything, is blocking you. Identify any negative feelings you have as a problem to be solved.
- ☐ BE persistent, if some things don't go the way you want, then ask what can you learn from that experience and go for it again
- ☐ DO use a coloured marker and write on it to celebrate progress and achievement

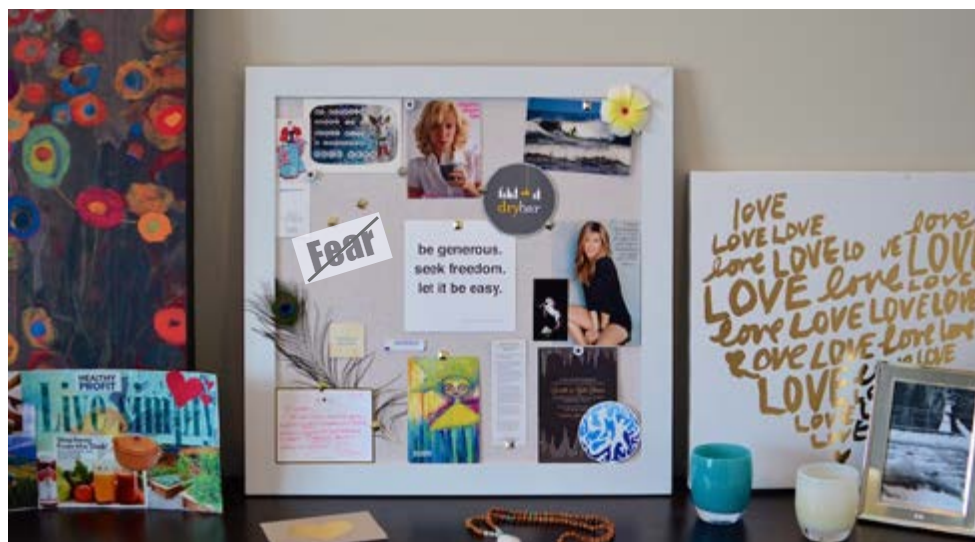


#### DON'TS

- ☐ DON'T use the word 'failure' - people who win accept this sort of experience just as 'feedback' and learning
- ☐ DON'T use the word 'try' - try is a word that if used, is already admitting an element of doubt .... just eliminate the word and stick to using words like 'I will'
- ☐ DON'T be afraid to add to the Vision Board or change it if you feel a real need
- ☐ DON'T become so accustomed to seeing it that you don't use it properly

## Vision Boards

They can be as simple or as artistic and complex as you want. It's your board.



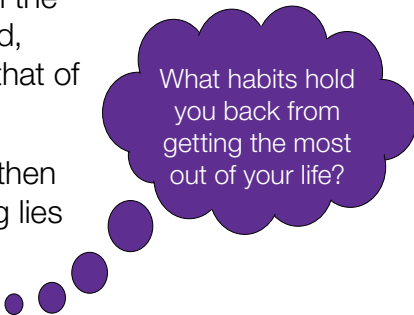
## PART 4: GOALS AND ACHIEVEMENT

### Habits

Habits are things that we do repeatedly such as cleaning your teeth, combing your hair, choosing healthy food over unhealthy, kissing goodnight, or going for a walk every morning. Habits start with conscious effort and then with repetition, and sometimes a bit of adjustment, the skills and capability increases and so our very clever brain puts them on automatic and places them deep in the unconscious mind so it can work more efficiently and effectively on other matters.

We develop habits throughout life and often without even realizing it. Habits such as slouching of the shoulders, putting your keys on a hook after you walk in the front doorway, smiling at strangers, criticizing people instead of finding good, telling lies, being afraid to share your own opinion because it is different to that of others, being right and never wrong, or even mumbling.

Some habits are helpful (if you put your keys in the same place all the time then you always know where to find them) and other habits are not helpful (telling lies often leads to more and more lies and an escalation of problems).



What habits hold you back from getting the most out of your life?

With a diagnosis of epilepsy, some people may develop a habit of hiding the fact they have it or be embarrassed after a seizure. However, it is important to remember that habits are a learned behavior, and so, can be 'unlearned' or change over time.

It is quite invaluable to examine your habits and determine which ones are helpful, which ones could do with a bit of tweaking, and which you should do away with altogether.

### Habits Exercise

- For as many days as you can (1 to 7), write down the habits you have used for the day. There are 'Note' pages at the end of the workook.
- At the end of the day/s, examine whether they are:
  - o **Beneficial** and in what way
  - o **Changeable:** Can you adjust the habit to improve the results. For example adjusting a habit of having 2 teaspoons of sugar in your coffee is easier than cutting sugar out altogether.
  - o **Removable:** Do you really need to do this, what if you didn't? What will happen if you continue to do this? How do I avoid or eliminate the trigger for this habit?
  - o **Alignment:** Do your habits match with your values, beliefs and goals? If they don't then what can you do about that?

## PART 4: GOALS AND ACHIEVEMENT

### Putting it all Together

If you can tick off these items for achieving the goals you want, then you are on the path to success.

My goal aligns with my values and beliefs	
Achieving this goal is within my control	
I can really 'see' it in your mind	
I can feel what it 'is' like to have it, be it	
I understand that there may be hurdles, but hurdles are made to be jumped or climbed or crashed through or gone around	
I know I can manage any self-talk or talk from others that could cause interference but I am in control	
I have created a Vision Board to use	
I am motivated toward moving forward and away from the same situation	
I have reviewed habits that relate to this goal and I can adapt to the necessary changes	
I am becoming more and more aware of my emotions and able to manage them for the results I need.	



## PART 5: COMMUNICATION & RELATIONSHIPS

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### Being an Effective Communicator

Communication is the foundation of life. Even when we are not speaking, our body is giving out signals to other people as to what is going on inside us - the way we are using our hands, our posture, our facial expressions (or lack of them), our breathing (depth and rate), skin tone (clear and clean, blushed, sweaty), and more. When we strive to listen to observe and understand the other person we become more effective in our communication.

Our relationships will benefit and we will be better understood by others.

#### The benefits of becoming a more effective communicator:

- Be better equipped to speak up, express and advocate for yourself (for seniors with epilepsy this may be with your family, with service providers, medical and clinical specialists and even with government departments)
- Greater understanding of yourself and other people = more successful relationships
- Prevents or minimizes misunderstandings
- Brings about more effective results in all areas of our life
- Understanding builds trust
- Increases your confidence and self-esteem ... and that of other people too
- Facilitates greater social interaction and involvement
- Increases your self-reliance and your ability to contribute to others
- Increases your ability to think critically, to question the thinking and behaviour of yourself as well as others.



## PART 5: COMMUNICATION & RELATIONSHIPS

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### Difficult Conversations

Approaching a difficult conversation with the attitude, 'this is going to be a difficult conversation', will likely result in a difficult conversation. Handling a difficult conversation knowing you are only in control of you will give you more flexibility and influence; therefore, more success in achieving the results you need.

Some people living with epilepsy have identified being in difficult conversations with family members, health or community providers; and discussed the need for information and tips on how to communicate effectively in these situations.

Difficult conversations can't always be planned in advance. The extra tips below will make a difference:

- ☐ Choose a time and place that most suits you. Sometimes it is best to leave a conversation until emotions have died down and privacy or quietness is available. Choosing the right time and place can be as important as choosing the right words and tone of voice
- ☐ Know the purpose and desired outcomes before you start
- ☐ Use the most appropriate type of language and words. Don't use 'fancy' words just because you can. It won't be helpful if the other person feels intimidated
- ☐ Understand that what the other person thinks and wants may be different
- ☐ Consider if you have any hidden agendas, any other motives
- ☐ If you think it will help, ask the person to hear you out fully before they respond - in doing so, make your point reasonably brief
- ☐ Ensure you allow the other person an equal amount of time, listening and asking questions to ensure you understand them
- ☐ Speak with dignity and respect
- ☐ Control your emotions. Don't allow the other person's words or behaviour intimidate you  
– you are the driver of your thoughts, behaviour and emotions.
- ☐ Ask for clarification if you are not clear on what they are saying
- ☐ Don't be afraid of asking for clarification in writing... "would you mind sending me an email with that in or have you an information sheet"
- ☐ Use silence when appropriate – it is a powerful tool when used in the right parts of a conversation
- ☐ Have a problem solving attitude
- ☐ If the conversation isn't going the way you want it to, don't be afraid of adjourning it and coming back at a later time

## PART 5: COMMUNICATION & RELATIONSHIPS

### Proactive language

Using proactive language and reframing negative communication will help you to be more confident in your communication. Reframing will help you look at things in a different way by choosing a positive focus instead of a negative one. It may be used in many ways within your own self-talk or discussions with others. It has the power of changing emotions, of changing habits and improving relationships. Reframing can disrupt a conversation that is becoming argumentative. Humour may also be used to reframe.

Reactive Language & Attitude / Negative Thinking	Proactive Language & Attitude / Positive Reframing
I can't do anything about it; I can't do that	I will explore the possibilities, the options. I don't necessarily have control over it but I might be able to use influence. I can focus on what I can do and not what I can't do.
That's just me, it's the way I am, been like it all my life	I'm not the same as I was five years ago. I have changed so I can change if I want to. I choose to be different in order to get different results.
They made me so angry, so mad, so sad	I don't have to 'be' a certain way because of someone else's behaviour. I can choose to be silent, I can choose to let it go. I choose my own feelings and responses.
I have tried that before and failed	I have done similar things that I am proud of, and that I can learn from, to be able to do this ....

As mentioned previously, we tend to default to the negative and reactive thinking. It takes practice and considered thought to reframe thinking and communication.

#### So let's practice...

Reactive Language & Attitude / Negative Thinking	Proactive Language & Attitude / Positive Reframing
Not being able to drive means that I can't access the community like I used to...	
I am feeling really anxious again, the other people at the local club are always staring at me...	
Your other examples?	

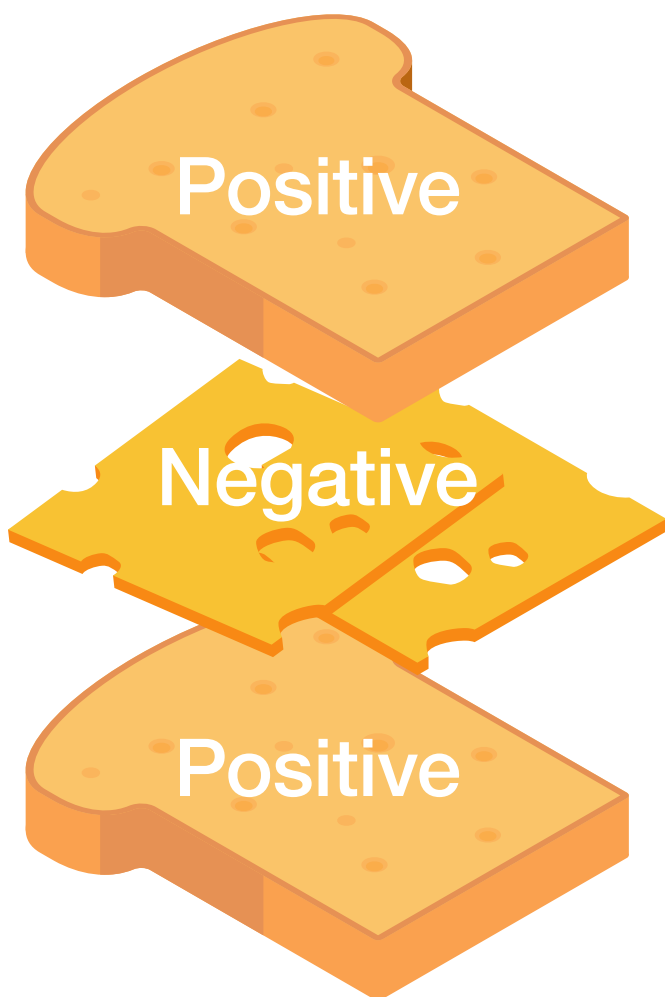
## PART 5: COMMUNICATION & RELATIONSHIPS

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### The Sandwich Method

The sandwich method is a tool to use when you are tackling a difficult conversation with someone and you want to do it in a positive way so the relationship remains in tact.

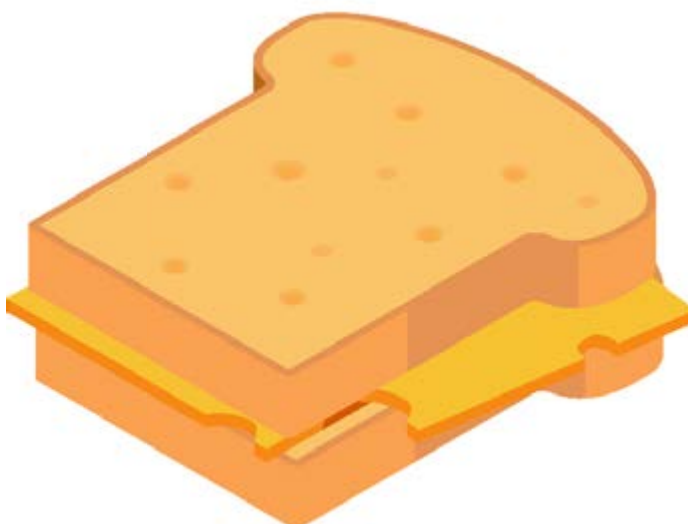
..... the bread, the cheese, the bread



"Honestly Alexandra you have been doing so great with keeping the house clean and well organised, it's made a huge difference

The only thing I would like you to do is to get into the habit of putting the vacuum cleaner and mop away in the laundry every time you have finished using it and even if you haven't finished using it, putting it out of the way somewhere please,

it will mean that there are nothing left lying around that I might trip over and especially if I have a seizure. You know - I really do appreciate what you are doing, you are so good to me".



## PART 6: MANAGING EMOTIONS & MEMORY

### Fear

Fear is a natural and complex emotion that has the purpose of protecting us. Instinctive responses of 'fight' sees us defend ourselves, while the response of 'flight' causes us to escape and avoid danger. In prehistoric times fear was what made us run and learn to protect our families and ourselves. Today though, fear is experienced for very different reasons and sometimes the level of fear experienced is not warranted.

The possibility of having a seizure is a common reason why people with epilepsy avoid or minimise the occasions they go out, socialize, 'go it alone', and join in the community. However, getting out and being with others is of vital importance for a person's mental health and wellbeing.

This is especially so for older people who can easily become isolated, lonely and then depressed.

Pushing through and at least reducing the fear experienced with epilepsy is something that people achieve to various levels.

When fear lingers and causes anxiety (fear of something that may or may not happen in the future) and it stops us from doing what we want to or need to do, it's time to seek help.

The suggestions below may help in reducing such fears:

- Having a 'seizure kit' with you (e.g. emergency information; medical information; phone; clothing etc.)
- Epilepsy alert ID in the form of a bracelet, key tag, necklace or even a mobile phone tag. These are a simple way to communicate to any responder if you are unable to speak. Choose one with a medical emblem. It should also contain a message that the wearer has epilepsy (and any other conditions)
- Epilepsy Alert App – there are a number of phone Apps for epilepsy. You'll find them by searching on the App Store or by contacting Epilepsy Queensland for more information. Some of these are for keeping a journal and some are alerts that will alert another person of a seizure
- Risk Assessments – this may be a visual checklist on the fridge before you go out – have I got – my phone, emergency ID, does someone know where I am going and return times?
- Do you have or need someone to accompany you?

**Tip: See the section on "use of visualisation" to help 'see' yourself doing the things you want to do.**

***A proactive attitude and a higher level of confidence makes going to new places and meeting new people all that much easier. Consider where the fear comes from and what is causing it. Is it the seizures alone or are there other fears involved?***

*If you are not going out because you are afraid, and are missing out on the things you would like to do socially it's time to speak out and seek help. You cannot get the right help if the right person doesn't know.*



## PART 6: MANAGING EMOTIONS & MEMORY

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### Mary's Story...

*I have lived with epilepsy for about 27 years, I am now 65 yrs old. My biggest mistake IN LIFE was & is giving into the fear that comes with the territory. The fear turned into depression, anxiety and low self esteem.*

*Fear is something that people with epilepsy experience and deal with at all sorts of levels. The fear of having a seizure isn't just about having one when out of the home, it can be at anytime, anywhere and in front of anyone. Strengthening your ability to manage your emotions, to push away memories of past experiences, and remaining as happy and as relaxed as you can will make a difference to the overall quality of your life.*

*Fear left unchallenged can persist and grow.  
Accept what you can't change, accept that there may be some risks.  
Put strategies in place.  
Investigate, challenge and problem solve your fears.  
If you allow fear to control your life then that's what it will do.  
Don't let it govern life and don't hesitate to seek professional help.*



## PART 6: MANAGING EMOTIONS & MEMORY

### Self-Esteem and Confidence

**Self-esteem** is the way you see and value yourself. It develops throughout life. Some people have a high positive self-esteem, while others have a low or negative self-esteem.

Positive influences, role models, and feedback throughout your life and the way you have filtered the information, focused and interpreted feedback leads to a strong positive self-esteem. When a person receives little or no positive reinforcers, then it is understandable that their self-esteem doesn't develop as well. Some people have a tendency to focus on all the negatives while others may focus on all the good – hence the saying 'are you a glass half full or a glass half empty person?'

Self-esteem levels influence the thinking, behaviour and decisions that people make throughout life.

**Confidence** is how you feel about your ability to do things, and it can be different in different circumstances. A person may feel very confident speaking out among a group of people they know, but become highly nervous if asked to stand up and speak in front of strangers or people they perceive to be more intelligent, more educated or more authoritative.

Here are some hints about developing and maintaining a healthy self-esteem.

- Know that the level of your self-esteem is changeable
- Your self-esteem may have been damaged due to some 'failures' or losses that you have experienced
- Note that failure is an important part of learning and development – when 'failure' is treated merely as 'feedback' it is seen as an opportunity to review what happened, learn from it and try again
- Learn to evaluate other people's words, behaviours and opinions – it's your choice to agree or disagree. You don't have to feel bad or a lesser person as a result

### Stigma & Self-Stigma

According to British Neuropsychologist Dr Sallie Baxendale, the stigma around epilepsy with misconceptions and outdated myths, is something that people with epilepsy experience on a regular basis. Dr. Baxendale believes the way to break down the stigma is through increased education to change social attitudes and by increasing the resilience of people with epilepsy. In her experience, people who attempt to keep their epilepsy hidden, generally have higher levels of anxiety and depression. Increasing resilience means people improve their ability to feel comfortable in revealing that they had epilepsy.

Stigma is when you are on the receiving end of negative and discriminatory attitudes, comments and behaviour from others and these tend to reinforce stress, anxiety, lowered self-esteem and confidence.

A stigma comes about from lack of knowledge, understanding and empathy. If many people took small steps to help educate others then this stigma will be weakened and minimised. Ask yourself "How can I influence others? How can I help educate those I meet?"

<sup>6</sup> [www.epilepsysociety.org.uk/epilepsy-stigma-worse-than-seizvrest-26-06-2014#xegnxpmzagq](http://www.epilepsysociety.org.uk/epilepsy-stigma-worse-than-seizvrest-26-06-2014#xegnxpmzagq)

## PART 6: MANAGING EMOTIONS & MEMORY

### Sadness, Grief & Loss

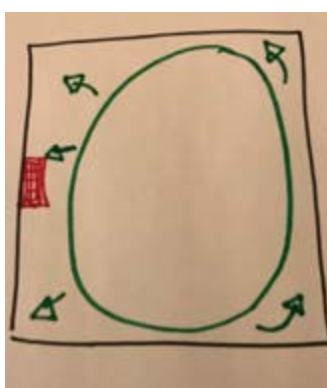
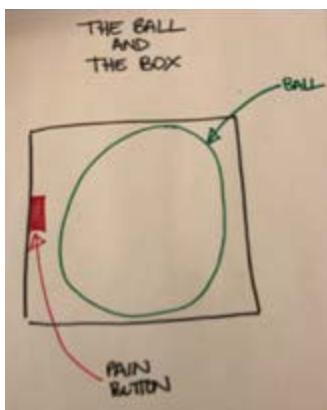
Sadness, grief and loss aren't emotions that are only experienced when a loved one dies. They can be just as powerfully experienced at the loss of other things that we value highly – such as changes in independence or relationships; job losses etc. It is understandable that many people who are aging, have experienced sadness, grief or loss associated with their epilepsy diagnosis. How you respond to it though - is highly important to your wellbeing and your future life and happiness.

The following is one person's experience worth sharing.

*"There often aren't enough words to describe the intense feeling of grief."*

*"It's complex, distinctly unique, and persistent. Not only that, but there's simply no right or wrong way to grieve a loss – all we know is that the pain of it can strike at any moment, unexplained."*

But one woman, Lauren Herschel, has shared an analogy told to her by her doctor, which many people have said perfectly explains what grief is really like. It's called the "ball in the box". (Find out more at: <https://psychcentral.com/blog/coping-with-grief-the-ball-the-box/>)



"After what has been a surprisingly okayish Christmas, I had a moment today in SuperStore," Herschel began on her Twitter account. "I saw a lady who reminded me of my 92yo grandma, who even in the early stages of dementia, completely understood that my mom died. I thought I'd share the Ball in the Box analogy my Dr told me," she wrote in a tweet that has recently resurfaced. So grief can be explained as this:

- There's a box with a ball in it
- There's a pain button on the inside of the box.
- Right when the loss occurs, the ball is at its largest in size, inching up against the walls of the box and incidentally pushing the pain button.
- In the beginning, the ball is huge. You can't move the box without the ball hitting the pain button
- It rattles around on its own in there and hits the button over and over. You can't control it - it just keeps hurting. Sometimes it seems unrelenting.
- Over time, the ball gets smaller. It hits the button less and less but when it does, it hurts just as much. It's better because you can function day to day more easily.
- But the downside is that the ball randomly hits that button when you least expect it.

## PART 6: MANAGING EMOTIONS & MEMORY

### Adapting to Change

We are creatures of habit, we get comfort from knowing what to expect, from sameness. But change is a continual thing in life even when we don't realize it. Every morning when we wake, we are not the same as the morning before – we have grown another day older and the experiences of the day before will have changed us.

Our ability to adapt to change influences how happy and successful we are.

People who are inflexible and don't adapt, are more likely to experience conflict in their lives. Here are a few steps to take to increase your awareness of how you approach change and the impact of not adapting well.

- Assess your current thoughts, emotions and beliefs about the change you are experiencing. How reasonable and accurate are they or are they exaggerated?
- Is the change something you have control over? You are only doing yourself harm if you hang onto emotions when you have no control
- Understand that change is inevitable
- Review some of the changes you have experienced in the past. You survived them and now there is this one. What can you learn from those experiences?
- Your choice of attitude will lead you down two different paths - so understand where having a negative attitude will take you and choose to adopt a positive attitude leading up the more beneficial path. If you need to, give yourself some dates or times to work by
- Challenge yourself by asking the four 'what if' questions below. They may seem strange but their purpose is to open the mind to different thinking.

#### Scenario:

"For years I have been the one to drive my grandchildren to school and now I can't."

<b>What will happen if I don't let go?</b> <ul style="list-style-type: none"><li>• I will stress more and become bitter about it</li><li>• I will or might experience health issues as a result of ongoing negative emotions</li><li>• I will continue to be unhappy</li><li>• I might be more 'snappy' for no real reason</li><li>• I will spend more time being angry and thinking about things that are outside my control</li></ul>	<b>What won't happen if I don't let go?</b> <ul style="list-style-type: none"><li>• I won't feel good or calm or happy</li><li>• I won't to feel motivated to do other things</li><li>• I still won't be able to drive the children to school</li><li>• I wouldn't know what it was like to let go</li></ul>
<b>What will happen if I do let go?</b> <ul style="list-style-type: none"><li>• I will feel peaceful and able to move on</li><li>• I will have the energy and focus to find other ways to be involved with my grandchildren</li><li>• I will help my daughter in other ways</li></ul>	<b>What won't happen if I do let go?</b> <ul style="list-style-type: none"><li>• The stress and bitterness</li><li>• Feeling 'knotted' in the stomach half the time</li><li>• The other things I can do to help my daughter</li><li>• New things I find to do with my grandchildren</li></ul>



## PART 6: MANAGING EMOTIONS & MEMORY

### Problem Solving

The very first step in problem solving is to recognize that you are experiencing a problem. Sometimes we put up with feeling awful, sad, lethargic or angry, without stopping to consider why. It helps to stop and give some thought to it, to recognize what you are experiencing is a problem – a problem that, with the right attitude and resources, might be broken into parts, possibly be avoided or at least the effects made easier to deal with.

*In order to solve or reduce the impact of any problem we must first recognize it as a problem and understand the specifics of it.*

When you experience any negative emotions - stop for a moment; think why and what it is that is causing you to feel that way!

Sometimes barriers or problems offer a challenge to find a solution. Importantly, some problems may never be resolved e.g. a permanent disability, the death of a loved one. It is helpful to determine whether it is a solvable problem or it is something that requires a different attitude, an acceptance, a letting go. Solving problems requires looking at the issue with different eyes and attitude than before.

Below is an example of the benefits of taking a problem-solving approach to issues.

*Barriers and problems in life can be physical and real but they can also be emotional, perceived – in our mind.*

*Bill could not cook because he did not have a stove (physical)*

*Bill could not cook because he always believed it was a woman's place to do the cooking' (perceived)*

*Problem solving approach:*

*Bill acquired a stove, attended some cooking classes, watched some online videos, practiced, failed a few times but learnt from those 'not so good' results, and after all that he not only became quite a good cook but now enjoys cooking. As a result of attending the cooking classes, Bill made some new friends, found he had an interest that could be discussed with other people, and he got a role volunteering in the kitchen at the community centre. In the process of all this Bill had 'let go' of his belief that he could not cook.*

*As with most problems, when they are solved other benefits arise*

## PART 6: MANAGING EMOTIONS & MEMORY

### Problem Solving

Another tool is to consider the 'flight, fight or problem-solve' approach to problems.

#### FLIGHT, FIGHT OR PROBLEM SOLVE

When a problem seems too massive, or too complicated, break it down into sections.

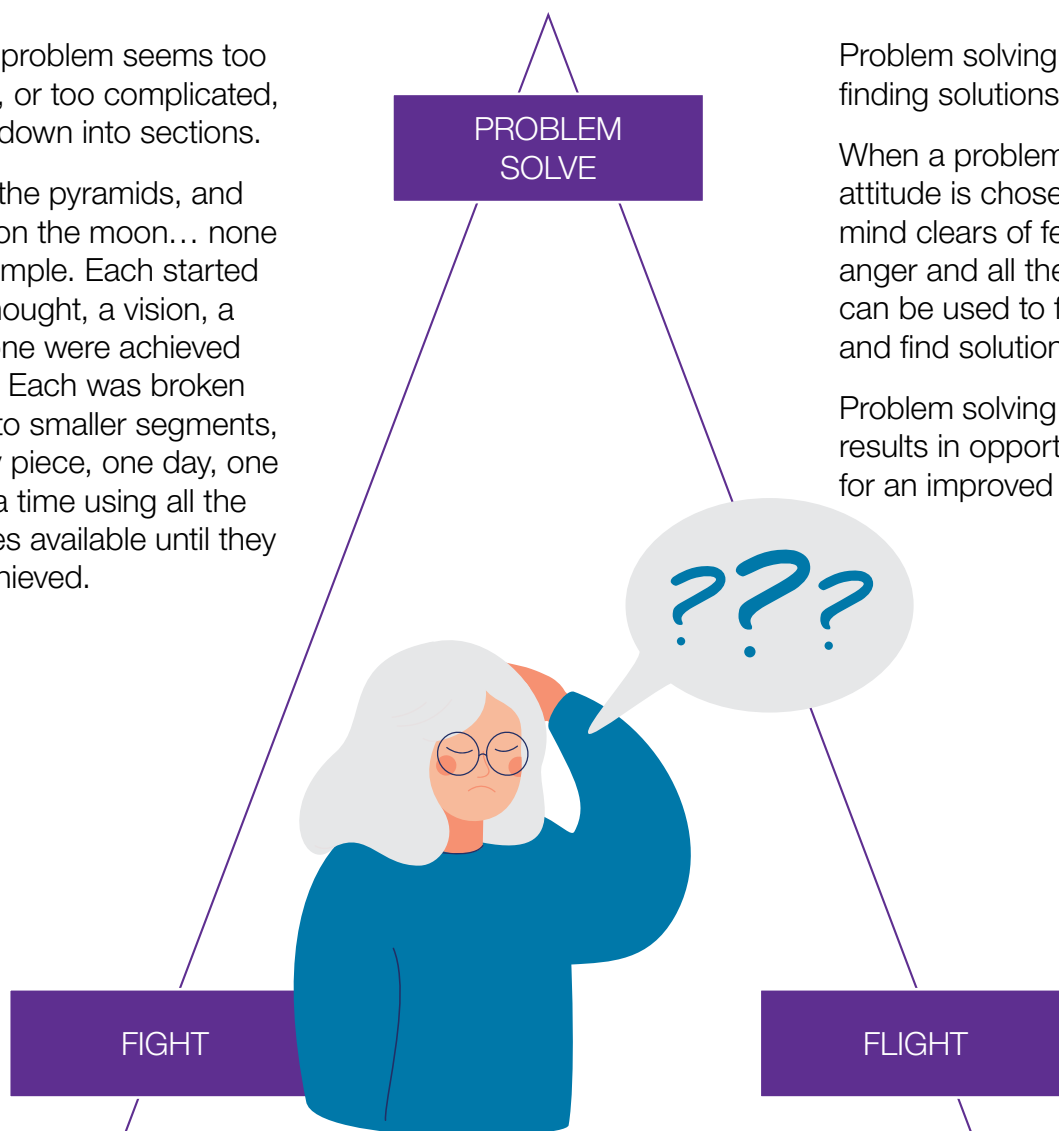
"Rome, the pyramids, and landing on the moon... none where simple. Each started with a thought, a vision, a goal. None were achieved in a day. Each was broken down into smaller segments, piece by piece, one day, one hour at a time using all the resources available until they were achieved.

PROBLEM  
SOLVE

Problem solving means finding solutions.

When a problem solving attitude is chosen, the mind clears of fear and anger and all the energy can be used to focus and find solutions.

Problem solving generally results in opportunities for an improved situation.



#### Personal Check-In...

Are there certain problems that you tend to fight, run away from (flight) or have a more considered problem solving approach?

How might you approach these differently for an improved outcome?



## PART 6: MANAGING EMOTIONS & MEMORY

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### Memory

Some lucky people have amazing memory functioning well into their 80s, however, most of us notice a few shortcomings in our memory functioning the older we get. Roughly 50% of people by the age of 60, wonder at different times if their memory is reliable. Having to walk back to where you were before to think what you have done with your keys or wallet, forgetting names – sound familiar??? Many medications for epilepsy also have side-effects that impair memory.

Insufficient sleep, stress, anxiety, and depression are other things that hinder memory functioning and that can be at any age. An older person with epilepsy has the added challenge of coping with the side-effects of medications that are often vital to managing seizures. While you may not be able to do without certain medications, the more self-aware you become, the more you practice to relax and manage your emotions, the better.



## PART 6: MANAGING EMOTIONS & MEMORY

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### Memory

#### Memory Hints

Use these as you can. Some will be helpful but with side effects of medications, some may not be helpful

- Attention: Paying attention is a key criteria to the storage of a memory, so strive to focus on the conversation or experience
- Repetition: Repetition is like winding a piece of cotton around and around and around a reel. It becomes thicker and stronger and easier to recall. The more you say it in your mind or out loud, the stronger the neural connection becomes and eventually it sinks into your subconscious and is automated. You don't have to think of the name of a loved one for example, it's 'just there'. The more you meet your new neighbour Joan, and talk about her and think about her, the stronger the memory of her face and her name becomes. Repetition is especially helpful for names, numbers, and locations.
- Imagery: Create an image, link a picture to it, visualise it. For example, how to get to an address, your shopping list, travel, geography .... actually 'see' your list in your mind
- Understand: when you comprehend and learn the why of something, it makes the memory more sensible and purposeful
- Mnemonics and association: e.g. Every Good Boy Deserves Fruit for the musical notes
- Chunking: break it down into sections e.g. phone and account numbers are easier if broken by spaces into sections
- Link new to old: a new memory to an existing one...
  - Nice to meet you Heather, I went to school with a Heather
- Preparation: Prepare to go to an event by planning ahead, visualize what you will be doing, ensure you are relaxed
- Health also plays a role in memory, so a regular sleep pattern and 8 hours sleep per night is important. Exercise boosts the amount of oxygen into the brain and eating whole foods within a healthy diet provides the vital nutrients it requires too.

#### Memory aids – examples

- Webster Packs for your medication from the pharmacist – this has the date and time of the medications, and helps to remind you when to take it, and if it has been taken
- a reminder App on your phone or on your Fitbit watch. There are quite a number of different Apps to choose from so check them out to find one that suits your needs best
- Pillbox with multiple compartments with alarms for times to take medications. This may help with medication compliance and independence.

## PART 7: WELLNESS

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Wellness is a term used to describe a state of having a healthy mind and body generally achieved through deliberate actions. The term is used as a healthcare approach to emphasizing prevention as opposed to treatment. Part 7, therefore, includes information on exercise, sleep, the importance of social contact, challenges associated with epilepsy and aging. The intention, as previously stated throughout, is to provide a basis from which you can work, seek more knowledge and strive to achieve the best possible level of overall wellness despite having epilepsy. Should you wish to obtain specific advice or join a wellness or fitness program, your GP is likely to have information available and be able to make appropriate referrals to one or more of the range of health professions in all these areas.

### Exercise

In today's world, the previously considered normal effects of aging are looked at by some physiologists and health professionals, not so much as symptoms of aging, but as symptoms of inactivity. Exercise/activity requires our hearts to pump blood (loaded with oxygen) from our hearts through our body and back via our veins (after the oxygen is used) to our heart.

Exercise works our lungs and our hearts maintaining the health of those incredibly vital organs.

Exercise is a real key to wellness throughout life and particularly in the latter years when there is a tendency to 'slow down'. Exercise has real benefits for someone with epilepsy, so long as it is done in a safe manner with support as and if required.

#### Benefits of exercise:

- ✓ Prevention of loss of muscle mass
- ✓ Reduction of body fat – helps achieve or maintain the ideal weight
- ✓ Lowers hypertension (high blood pressure)
- ✓ Improves glucose tolerance and reduces insulin resistance
- ✓ Helps maintain bone mass and prevent bone loss
- ✓ Helps maintain joint flexibility
- ✓ Reduces risk of falls, injury and back pain
- ✓ Helps increase life expectancy
- ✓ Releases chemicals such as endorphins and serotonin, to improve mood. It can reduce stress levels and symptoms of mental health conditions such as anxiety and depression.



## PART 7: WELLNESS

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### Tips for Incorporating exercise into your day

It's great if you are able to access a gym or fitness centre and attend regularly - even if only 3 times a week, but it is important to note that even if you achieved three visits of one hour a visit, that leaves a great deal of time in between.

An effective addition to increase your level of activity is to incorporate it into your daily life. You need to be mindful of risk and injuries, so please speak with your GP about a plan that is right for you.

- ☐ Create new habits ... morning &/or night brisk walk around the garden, block, or park
- ☐ Have the right attitude with your end goals in mind as you do it .... 'Just do it!'
- ☐ Buy yourself a 'FitBit' or similar – these watches tell you the time and record how many steps taken each day, heart rate, reminders and much more – a great personal motivation tool
- ☐ Join a local walking or fitness group
- ☐ Incorporate strength training to keep bones strong
- ☐ If the weather is not good, don't let that stop you. Exercise inside at home, in the garage or even go to the local shopping centre and walk around in their air-conditioning
- ☐ Take up yoga, pilates, golf, bowls, cycling or swimming (if safe for you), or learn to dance
- ☐ Walk your dog or your neighbour's dog (with their permission of course) ... or just walk your heart and lungs!
- ☐ Dance to some music at home where no-one needs to see you
- ☐ Hold onto the back of a chair and work your legs
- ☐ Use a phone call as an opportunity to walk around the house
- ☐ Hire a personal trainer with a few others if you need to reduce the cost or get a referral to see an exercise physiologist. Many of them have small group classes, which means opportunities to make new friends
- ☐ Walk at different times at different places, make it an adventure, make it an opportunity to smile and say hello to people
- ☐ Check the Internet for exercise videos

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**Tip:** *Ensure you drink plenty of water*

*Don't do rigorous exercise if feeling unwell*

*Consider exercising with another person, especially when swimming*

*Don't over-exert yourself*

*Warm up, stretching and warm down are important*

*Talk to your doctor about suitability of particular activity for you and your seizure history*

## PART 7: WELLNESS

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### Sleep – Insufficient Quantity and Quality

Getting sufficient sleep (ideally 8 hours per night) and good quality sleep is important to your wellbeing. Although there is still much to be found out about the purpose of sleep, Scientists believe that sleep is important to:

- Maintain physical health-including the heart, blood vessels and immune system
- Organize/sort and store memories making adjustments to the brain and its neural pathways
- To heal and grow
- To maintain ability to concentrate, focus, maintain a good appetite and weight
- Enhance learning and memory

Sleep is a challenge for some people in normal circumstances as they grow older. For people with epilepsy, sleep problems are a double-edged sword; epilepsy can disturb sleep and sleep deprivation may aggravate epilepsy. If sleep is high on your list of challenges it is suggested that you seek help from your GP or epilepsy specialist. A sleep study may be recommended to identify any other sleep disorders that may impact on quality of sleep.

Below is a list of suggestions to enhance sleep quality

- Develop a 'going to bed' routine including a regular bedtime. You might even include a warm bath or shower as part of the routine
- Reduce stimulants especially later in the day and towards bedtime (tea, coffee, chocolate, exciting television programs)
- Limit alcohol consumption – one or two drinks per day is recommended. The belief that alcohol aids sleep is a myth
- Eat your evening meal as early as possible – ideally three hours before going to bed
- For at least half an hour prior to bed, stop watching television or using technology
- Exercise: regular exercise, especially if part of a routine, has been shown to impact positively on mood and to boost the quality and quantity of sleep. Hard exercise should be done early in the day
- Sleep on your side if that makes breathing easier for you
- Stress/worry is a common cause of having difficulty getting to sleep, waking up in the night and then getting back to sleep. Exercise, even just a short amount, is a healthy way of relieving stress, changing mood and sleeping better
- Mind-body exercises are helpful for many people: Yoga, meditation, gentle music, and relaxation techniques (see mind-body exercise below).



## PART 7: WELLNESS

### Sleep – Insufficient Quantity and Quality

What you believe about yourself as a sleeper also has an impact. How many times have you reinforced to yourself that you are a poor sleeper .... thinking it, telling others .... each time you do, you reinforce the belief and the behaviour. Catch yourself and throw that thought, those words back. Congratulate yourself on being an awesome sleeper and having a great nights sleep .... even if it wasn't quite that good!

The Sleep Health Foundation (Australia) has a very broad range of Fact Sheets about sleep including (but not limited to) the following topics:

- Ageing and Sleep
- Depression and Sleep
- Facts About Sleep
- Sleep Myths
- Understanding and Helping Poor Sleep
- Anxiety and Sleep
- Does Sleep Matter
- Herbal Remedies and Sleep
- Common Sleep Disorders

Source: <https://www.sleephealthfoundation.org.au/fact-sheets.html>

### Mindfulness

Mindfulness is a beneficial technique that strengthens the brain and assists in reduction of stress. It strengthens the focus on 'the now' and takes away focus on the past and the future, so the past is over and done with and cannot be altered and the future fears may never come about.

With epilepsy, there are of course many different challenges that people experience, and the control of your mind and thoughts is one of those challenges.

Mindfulness teaches people to focus on even the smallest of things such as eating your meals slowly, enjoying every mouthful and the full experience of this; or walking in your garden and appreciating everything there is to see, every sound you hear, every step you take.

If you are interested in learning more about Mindfulness and the effect this has on your brain, please refer to the Beyond Blue resources (written information and video), as per link below.

[https://www.beyondblue.org.au/personal-best/pillar/in-focus/the-effect-of-mindfulness-on-your-brain?fbclid=IwAR2Jk0n1gfo\\_qrnpHjIRF897kVhpYIAWiOv-ouRE1\\_a1DEt6cS78Wy-X44](https://www.beyondblue.org.au/personal-best/pillar/in-focus/the-effect-of-mindfulness-on-your-brain?fbclid=IwAR2Jk0n1gfo_qrnpHjIRF897kVhpYIAWiOv-ouRE1_a1DEt6cS78Wy-X44)

The following is an example of a Mindfulness Script as developed by Very Well Mind

([https:// www.verywellmind.com/a-basic-mindfulness-meditation-script-for-sad-3024820](https://www.verywellmind.com/a-basic-mindfulness-meditation-script-for-sad-3024820)).

As with other tools suggested in the Workbook, let yourself be open to this, you may get a lot out of it.

## PART 7: WELLNESS

### Mindfulness



#### The following is a mindfulness meditation script

This script is based on basic meditations, and specifically those for coping with anxiety. Choose a quiet place and time to practice your meditation. You might also wish to set a timer to signal the end of your meditation; anywhere from 20 to 40 minutes is a typical length for practice.

If you would prefer to listen to the script, you could also consider recording yourself reading the passage below and then play it back to yourself through headphones.

Begin your meditation by choosing a position. Sit in a chair with an alert but comfortable posture, back straight, hands resting in your lap and feet flat on the floor; or you may like to lay on the ground (pillows may help).

- Make sure that you're balanced and not straining. Loosen any tight clothing and close your eyes
- Gradually notice the stillness of your body. Relax your stomach, chest and shoulders, and begin to focus on your breath
- Breathe in deeply through the nose, allowing the air to flow down to your diaphragm, and then release
- Repeat the breath, allowing the air to gently flow through. Notice a sense of calm as you breathe out. Release tension and stress as you gradually find a comfortable rhythm for your breathing
- As you breathe in and out, notice any thoughts or feelings that you have
- You might start to worry about the future or think about the past—it's normal for your mind to wander. Some feelings and thoughts might be very distressing, but do your best to observe and not judge
- Make a note of the thought or feeling and what it is: maybe you worried about an upcoming social event or thought about a conversation that didn't go so well
- If a negative thought or feeling grabs your attention, make a note of it and then return to focusing on your breath. It's natural for your mind to wander to your social and performance fears, but try not to be critical of yourself
- Notice the thought or feeling, but don't follow it, and don't let your mind pursue it. Recognize that it's simply a thought: it's what your mind does. You can notice it and then let it go
- Picture yourself at the beach, lying on the warm sand
- A refreshing breeze blows in and you feel relaxed. Imagine your thoughts and feelings are like the wind blowing or the waves rolling, and continue with your breathing, letting everything become the wind and the waves
- Feel how the waves come and go. Remain calm, and let your thoughts move and change. Breathe

## PART 7: WELLNESS

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### Mindfulness

- Intentionally bring to mind a situation that you fear. Imagine yourself talking to strangers or giving a speech. Sit with the uncomfortable thoughts and feelings that this situation brings, and simply let them be, without resisting
- Relax and let the thoughts and feelings gradually dissolve. Resistance will make the distress stay, while acceptance will allow the negativity to dissipate
- Remember that you will always experience some anxiety; it's impossible for it to completely disappear. Instead of resisting, learn to welcome your thoughts and feelings, accept them, and then feel how they float away
- When you do find yourself in a moment of happiness during your day, grab hold of it, keeping the feeling in your awareness
- Count to 15 seconds, allowing your brain to start establishing and strengthening new pathways. The more you use these pathways, the deeper the grooves become. Happy thoughts will eventually fill those grooves
- Gradually, when you are ready, bring your attention slowly back to your breath. Then, move to your body and your surroundings. Move gently, open your eyes, and stretch.

### The Need for Socialisation

Psychologists and others studying human behavior believe social needs are one of the highest needs of humans, after physical and safety needs. Humans need and benefit from interaction with and the company of other humans.

Connecting with others provides us with:

- friendship, love and a sense of belonging
- someone to trust and share problems with
- someone to communicate and build relationships with
- an avenue to share who we are with others

Socialisation also reduces isolation and loneliness, and the activity of interacting with others benefits our brain and cognitive health.

For many people the experience of sharing a meal with someone and having a good conversation becomes less and less frequent. Having people to relate to, to share experiences with and to experience some humour and laughter is very important. Loss or lowered independence can make this more challenging though. It is important therefore, to actively seek opportunities to be with other people and to participate in family, group and community activities. Check your local newspaper, they are usually a great source of information. Reach out and organize to attend events. Problem solve if there are hurdles to be jumped over!

## PART 7: WELLNESS

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### The Need for Socialisation

#### Dealing with Reduced Independence

As we age, reduced independence is one of the main challenges experienced by many people. It helps to prepare yourself for all the possible changes and to think how you can reduce the impact and to plan ahead. The impact of a diagnosis of epilepsy, though, may mean that independence is reduced earlier in life.

Here is a list of some ideas to help deal with reduced independence

- Write down all the things you DO have control over
- Endeavour to find new things to boost your feelings of independence. For example: organizing get-togethers, for family/friends to come to your home; taking up a new interest or hobby; planning the food for the week; and shopping online
- Tell your loved ones and friends how you feel. Let them know if they are being over-supportive or 'micro-managing' you. Be as specific as you can. Work out and discuss how you would like them to help you while still promoting your feelings of independence. Discuss the things you can still maintain independence with
- Think about all the people that you have helped in the past, people you have known who weren't independent
- Help someone else in some way
- Make every effort to keep an open mind, to find acceptance, to 'let go' of the things and feelings that do you no good
- Review the challenges you have experienced in the past – can you learn from them?
- Hone your skill of patience: be patient with yourself and with others. Ask others to be patient with you too if you feel a need
- Learn something new
- Determine what things give meaning and purpose to your life
- Understand that change is an inevitable part of life.

Additional support is also available: Beyond Blue (P: 1300 224 636) or My Aged Care (P: 1800 200 422).

#### Mutually Beneficial Friendships

Reliance on others can impact emotional well-being and might restrict a person's ability to attend engage meaningfully within their community.

A suggestion to manage feelings and practicalities of reliance, is the development of 'mutually beneficial friendships.' This refers to a group of people/friends who all have something to contribute towards the benefits of the group or individuals belonging to the group.

***Think deeply and find what it is that you can do or already do to help other people. Think whether you are focusing too much on what you 'can't do' and need to focus more on what you 'can' do. If a person drives you places then what skill, knowledge, actions, or strengths can you share? What can't they do that you could do for them?***

***Giving makes us happier.***

## PART 8: PRACTICAL SOLUTIONS

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### Reducing Risk of Falls

The risk of having a fall and the seriousness of the consequences increases as we age. Often the factors that lead to a fall are multiple. They can be intrinsic (within the person – such as fear and inattention) and extrinsic (external, hazards, environmental matters). Other factors can include, for example: poor reaction times, muscle weakness, poor flexibility and balance, trip hazards, other health conditions, medications, and even inappropriate footwear. Similarly, many seizure types result in falls.

It is wise to consider all these things and if you have concerns, or have had one or more falls, then ask your GP for a falls assessment to be carried out. The falls assessment will also consider other recommendations, which may include, bone density scanning, exercise and diet changes, aids/equipment to assist with mobility etc.

If falls are something that you experience as a result of seizures then assessing risks at home and making your home safe is something you can do. You may be able to obtain a referral to an Occupational Therapist via your GP or local hospital. The role of an Occupational Therapist is to assist in finding ways (including methods, equipment and home modifications) to overcome challenges of participating in activities of normal life and/or work. You can view more information about Occupational Therapists at:

<https://ahpa.com.au/allied-health-professions/occupational-therapy/>

Ideas for home safety precautions include:

- ☐ Avoiding hard floors or covering them with a softer and non-slip alternative
- ☐ If there is a choice, avoid having a house or outdoors area with stairs and steps; or investigating ramps
- ☐ Minimising the amount of obstacles throughout the house and in particular obstacles that could harm if fallen on such as hard or sharp objects. Find soft padding to cover objects where possible
- ☐ Avoid having furniture with sharp corners and edges
- ☐ If you have glass doors then can they be double glazed or can furniture be used to prevent falling through them
- ☐ If night time seizures are experienced then can the bed be reduced in height and can other items be moved away of a night or a doona or scatter cushions provide a soft landing





## PART 8: PRACTICAL SOLUTIONS

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### Pets

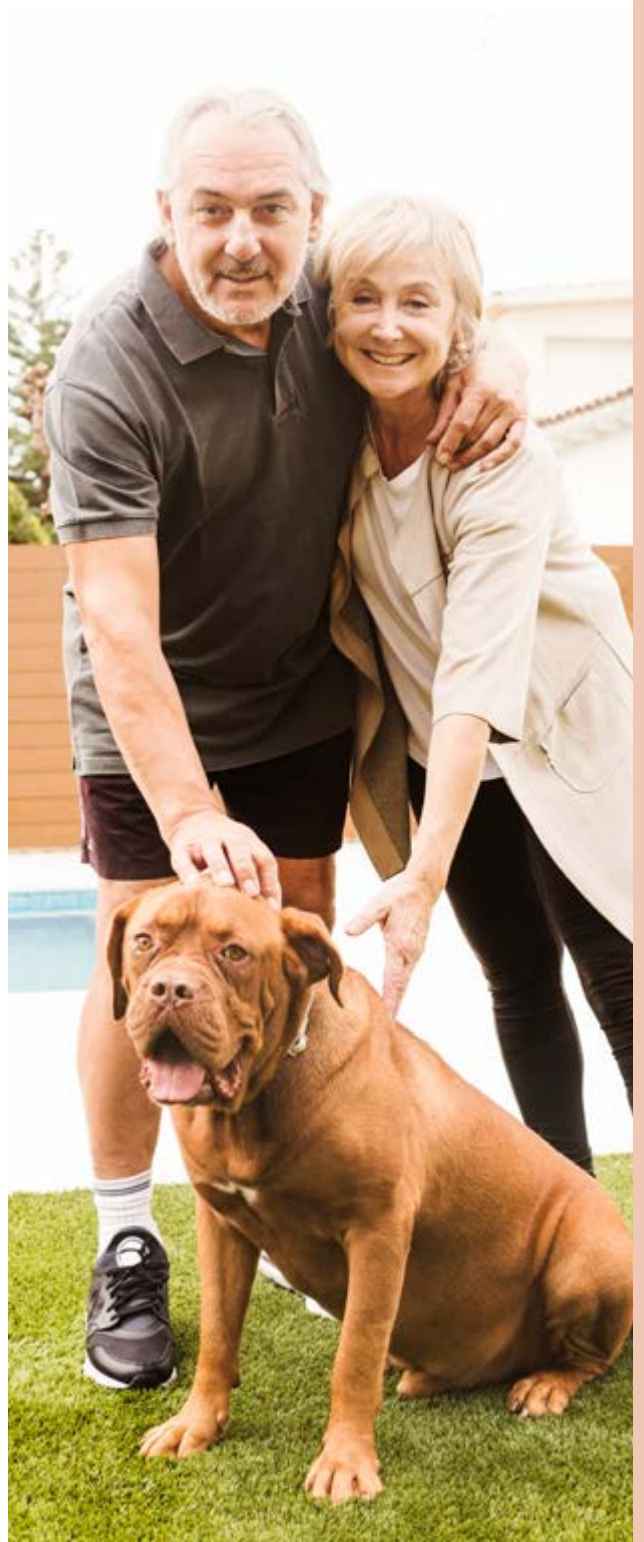
For many, pets are simply another member of the family. People have conversations with them, cuddle them, care for them, and take them out. Pets are a topic of conversation when talking to other people and an ideal introduction agent when going for a walk.

Whether it is a dog, a cat, a bird or even a guinea pig, having a pet especially at times when a person is experiencing loss and sadness or at risk of loneliness in any way, helps bring so much warmth and love into a person's life.

The benefits of having a pet might be any one or more of the following:

- Something/someone to care for and be responsible for
- Provides a sense of purpose
- Companionship, comfort, cuddles, affection
- Helps reduce feelings of isolate and loneliness
- Helps reduce stress levels and even brings laughter and fun into a person's life
- Increases social activities and topics of conversation
- Pets that can be walked provide a reason and motivation to get out and exercise
- Some pets can be of support for people who have experienced trauma
- Some dogs are chosen for training as assistance dogs although some are apt to be supportive in some way even without assistance training

These benefits have been found in studies to have real health benefits that include decreased blood pressure and cholesterol levels.





## PART 8: PRACTICAL SOLUTIONS

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### Level of Carer/Family Availability and Support

The contribution of parents/spouses/carers and family for many people is invaluable. Some carers will have provided support for many years and so will have acquired a great deal of skills and knowledge along the way, in which they can impart to others who may provide supports.

However, keep in mind, there is always something to learn - both for the benefit of the person with epilepsy and for the benefit of the person providing the support. Information such as:

- ◇ Details of the specific type of epilepsy
- ◇ Seizure management – particularly as research evolves and new practices are available
- ◇ Seizure first aid
- ◇ Risk Assessments
- ◇ The impact of empathy & understanding of the physical and emotional challenges
- ◇ Willingness to provide transport in a supportive, “no problem” manner
- ◇ Availability and planning
- ◇ Emotional issues such as self-esteem, loneliness, anxiety, stress, depression
- ◇ A person’s need to access and be involved in the community

Epilepsy Queensland provides a range of forums to share and to learn about epilepsy, both for the person with epilepsy and for their carer/family.

The services include information, support and counselling, in-service training, community awareness and education, and advocacy.

[www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au) or the Helpline is 07 3435 5000 (9am to 4pm Mon-Fri) or you can email to: [services@epilepsyqueensland.com.au](mailto:services@epilepsyqueensland.com.au)



## PART 8: PRACTICAL SOLUTIONS

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### Learning to Live Without Driving

Having the independence of driving is a common expectation, but many people diagnosed with epilepsy (and numerous other illnesses) will have their driver's licence suspended or cancelled. For these people life does go on and learning to adapt to change will be your strength. Learning to accept what you can't change and taking a problem solving approach may present you with new opportunities that you hadn't thought of previously.

Here are some suggestions and information to help you. Try not to dismiss them quickly but stop and consider each one and challenge yourself to find solutions.

- Find another person/s in similar circumstances (it doesn't have to be someone with epilepsy) and form mutually beneficial friendships
- Get a map of your local area
  - o Decide how far you could walk
  - o Draw a circle around that area
  - o Find out all the things of interest and what community groups and centres are within the circle
  - o Find out what public transport is available.
- Explore the possibilities of walking with a small group of neighbours or friends to different places
- Explore if there are people you know who you could car pool or rideshare with
- Apply for taxi vouchers (see below) to reduce the cost of taxis
- Find out if you are eligible for any government funding for transport and/or social support:
  - o If you are over 65 (50 years for indigenous people) contact My Aged Care for information
  - o If you are under those ages you may qualify for funding under NDIS (National Disability Insurance Scheme)
- If you can't get into the world outside as much as you would like, then consider what you can do to bring people and the world to you
- Through all of this retain a positive, problem solving attitude – it will serve you best

## PART 8: PRACTICAL SOLUTIONS

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### Taxi Vouchers

The Taxi Subsidy Scheme (TSS) subsidises taxi travel—half of the total fare, up to a maximum of \$25 per trip—for people with severe disabilities. Taxi subsidy vouchers are available from Queensland Transport based on the severity of your condition. Terms, conditions and application forms are at:

<https://www.qld.gov.au/disability/out-and-about/subsidies-concessions-passes/taxi-subsidy>  
or Telephone 1300 134 755

### Flexilink & Community Transport

All eligible seniors using a Senior go card or a Seniors Card +go will be able to travel free of charge on Transport for Brisbane buses, CityCats and ferries on selected off-peak services from 1 October 2019.

<https://translink.com.au/travel-with-us/taxi-and-community-transport/flexilink-and-community-transport>

Phone translink on 13 12 30 to find out more about this



## PART 9: SUPPORT SERVICES, RESOURCES AND LINKS

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### Companion Card

A Companion Card is issued by the state government to address the needs of people with a disability or lifelong need for support. The card is issued in the name of the person who is being supported (valid for 5 years), and can assist with the costs of getting out and about with the support of a companion. For example, the card holders receive a second 'companion' ticket at no charge at participating venues and on public transport. It is also exempt from any booking fees.

The Companion may be a paid or unpaid assistant or carer, a family member, friend or partner.

More information available at:

<https://www.qld.gov.au/disability/out-and-about/subsidies-concessions-passes/companion-card>

### Seniors Health Care Card

You are eligible for a Seniors Health Care Card if you have reached pension age, which for most people is 65 years of age, younger if you are indigenous. There are a several other criteria including not receiving a Veterans' Affairs payment, meeting an income test and that you are an Australian resident currently living in Australia.

The benefits of the Seniors Health Care Card are: cheaper medicines, bulk billed doctor visits, and a higher refund when your costs reach the Medicare Safety Net. Other benefits may include reductions in power bills, property and water rates, ambulance, dental and eye care costs, and public transport.

You can visit Centrelink or the link below to find out more and to apply:

<https://www.humanservices.gov.au/individuals/services/centrelink/commonwealth-seniors-health-card/who-can-get-it>

### Social Workers

When personal life or family issues seem out of control and you don't know where to turn, what to do and you have no-one really to turn to, then many people will phone an organisation such as Lifeline or Beyond Blue. Social Workers are qualified in the areas of human behaviour and development, life cycle stages, families and community, disability, and health including mental health. They assist people to identify where and how their lives can be changed and are able to make referrals and connect people to the appropriate support services.

Social workers work in many different settings including aged care organisations, mental health services and public and private hospitals. They generally provide counselling, therapy and group sessions and can also assist with coordination and care management. If you have concerns that may be helped by a Social Worker then your GP may be able to assist or the nearest hospital or you can locate one near you on:

<https://www.aasw.asn.au/find-a-social-worker/search/>

## PART 9: SUPPORT SERVICES, RESOURCES AND LINKS

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### Funding for Services

#### Queensland Community Support Scheme

- About: The Queensland Community Support Scheme (QCSS) is a new scheme that provides supports to people who, with a small amount of assistance, can maintain or regain their independence, continue living safely in their homes, and actively participate in their communities.
- Eligibility: people who have a disability, chronic health condition, mental health condition or other circumstance that impacts on their ability to live independently in the community
- Registration: via Queensland Community Support Scheme Access Point on 1800 600 300 OR online at [www.qld.gov.au/qcss](http://www.qld.gov.au/qcss)

#### National Disability Insurance Scheme (NDIS)

- About: Funding for supports and services for Australians who have permanent and significant disability. More information [www.ndis.gov.au](http://www.ndis.gov.au)
- Eligibility:
  - o Aged between 7-65yrs old;
  - o Australian resident;
  - o Require support because of a permanent and significant disability
- Registration: An Access Request can be started over the phone by calling the NDIA on 1800 800 110 between 8am – 8pm.

#### Over 65 years of age:

##### Supports through My Aged Care

- About: Contacting My Aged Care is the first step in the aged care journey. They can provide information about services to help you stay in your own home, or what to expect in an aged care service.
- Eligibility: over 65 years and complete an assessment with My Aged Care
- Registration:
  - o phone 1800 200 422
  - o phone 131 450 for translating/interpreting services OR
  - o online at the website <https://www.myagedcare.gov.au/>

For more information on eligibility and how to access these services, please contact Epilepsy Queensland.



## PART 9: SUPPORT SERVICES, RESOURCES AND LINKS

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### Future Life Planning

In the latter years of life, creating a plan of your choices and decisions can help reduce stress and anxiety. Creating a plan means that you make decisions and choices about the remainder of your years while you still have the capacity to do so. It is not necessarily a topic that people have pleasure in thinking about or discussing but, people do report, while some aspects can be confronting, it is a 'weight off their shoulders'. Not all scenarios can be foreseen but having the right legal papers in place and information recorded in writing covers most important things.

A Statement of Choices, Advance Care Planning document is available from the Queensland Government at the Office of Advance Care Planning. Email enquiries to [acp@health.qld.gov.au](mailto:acp@health.qld.gov.au) or telephone 07 3710 2290.

The form can be downloaded at [www.mycaremychoices.com.au](http://www.mycaremychoices.com.au). This document will help record your wishes, values and beliefs to guide those close to you to make health and support decisions on your behalf, if at some stage, you become unable to make those decisions.

An Enduring Power of Attorney (for health and personal matters) and an Advanced Health Directive is all part of the advance care planning. You might also consider some of the following:

- ☐ Prepare a list or affix labels to indicate what possessions go to who
- ☐ What will happen to my pet
- ☐ Prepare an emergency contact list and/or instructions and place it in a prominent place so that emergency workers could use it
- ☐ Make sure your next of kin and family know your wishes and what solicitors you use
- ☐ Openly discuss your wishes with family (including aged care choices and funeral choices)
- ☐ Repairing or strengthening any relationships that might need it





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- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5573739/>
- <http://www.mindtools.com/memory.html>
- [healthier.qld.gov.au](http://healthier.qld.gov.au) – vids/exercises
- <https://www.health.qld.gov.au/stayonyourfeet/for-professionals/about-risk-factors>
- <https://www.humanservices.gov.au/individuals/services/centrelink/commonwealth-seniors-health-card/who-can-get-it>
- <https://www.cdc.gov/healthypets/health-benefits/index.html>
- <https://www.epilepsy.com/learn/age-groups/seniors-and-epilepsy/falls-during-seizures>
- The Ball in the Box: <https://twitter.com/LaurenHerschel>
- <https://www.beyondblue.org.au/docs/default-source/policy-submissions/stigma-and-discrimination-associated-with-depression-and-anxiety.pdf> (Stigma and Discrimination info paper)
- <https://www.blackdoginstitute.org.au/>
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- <https://www.sleephealthfoundation.org.au/sleep-terrors.html>
- <https://agec.uams.edu/2018/07/24/the-importance-of-socialization-as-we-age/>

## ANNEXURES

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[https://www.epilepsy.org.au/epilepsy-and-risk\\_seizures-and-injury/](https://www.epilepsy.org.au/epilepsy-and-risk_seizures-and-injury/)

Epilepsy Foundation (USA) is another source of information about sleep and epilepsy

<https://www.epilepsy.com/learn/triggers-seizures/lack-sleep-and-epilepsy>

<https://www.epilepsy.org.au/wp-content/uploads/2017/10/EAA-FIRST-AID-POSTER-2017-New-LOGO.pdf>

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