

A practical journey to living well with epilepsy

Sue Mitchell

Epilepsy – a ‘spectrum’ condition

- Over 40 different types of epilepsy
- For some, epilepsy ‘plus’ – other conditions
- Everyone with epilepsy experiences it differently

An individual condition –
an individual response

What does 'living well' look like?

- Seizure freedom
- Opportunity and choice
- Education and training
- Employment
- Relationships
- The option to have a family
- Self-esteem
- Fulfillment
- Happiness
- Other important aspects personal to you

• Confidence

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Living well for Samuel, 6



I've shared Samuel's achievement
to help highlight epilepsy.

Tracey Jones

4

Living well for Thea, 8



I love reading now and mum says “This is an amazing achievement” for me.

Thea and mum Gina

Living well for Andy



Myth-busting is really important....The public need to realise that this condition is something that many people live with on a daily basis.

Andy Deighton

What does your 'living well' look like?

Step 1: a 'living well' plan



Step 2: make your plan achievable

- Make your plan about today
- When something changes – draw a new plan
- Review your plan – once a month, every six months, annually
- Plan your steps to success:
 - Break each goal down into a series of steps
 - Review and adjust – keep things achievable
 - Keep a journal of your successes – and plan a reward!
 - Share your successes and challenges

Step 3: taking action

- Think it...
 - A positive attitude
 - Clarity on what you want – make your plan your friend
- Know it...
 - Be informed
- Do it...
 - Be an active partner – with your doctor, your school, your employer
 - Take action

...and working with others

- Influencing new and better laws
 - Equality and ending discrimination
 - Education and employment
- Working for access to the best epilepsy care and treatment
- Tackling myths and misunderstandings:
 - Reducing stigma
 - Helping the public learn about epilepsy
 - Raising awareness of what to do when someone has a seizure

Step 4: some practical tips

Looking after your epilepsy

- Understand your seizures and any seizure triggers
- Take control of your medicines and treatment
- Learn how to manage your seizure triggers
- Help others to understand your epilepsy
- Look for a self-management course or programme

Helping your health professional look after your epilepsy

- Be an active partner in your care and treatment
- Keep a seizure diary – seizures, triggers, side-effects
- Keep a list of questions for your next appointment
- Set up a care plan
- Regular reviews:
 - How is everything going?
 - Has anything changed?
 - Written notes and questions

Education and training

- Individual healthcare plan – an agreement with the school
 - What to do in the event of a seizure
 - The child's needs during and after a seizure
 - Access to medication
- Keep a school diary
- Work with staff and healthcare provider – a partnership
- Suggest training for school staff
- Extra support at exam time

Employment

- Think about if and when to disclose your epilepsy
- Find out about any regulations
- Support organisations
- Care plans and risk assessments
- Consider things like the impact of shift work
- Will you have or need trades union support?
- Inform colleagues on what to do in the event of a seizure

Social life

- Epilepsy is only a part of who you are
- Build a social network of people who will support you
- Explain your epilepsy and how your friends can support you
- Don't allow others to pressure you into taking risks
 - Too much alcohol
 - Driving without a licence
 - Doing activities without necessary precautions
- Try to understand those who may overprotect you

- **Having a family**
 - Child bearing age? Ask for pre-conception counselling
 - Check out the facts and plan ahead
 - Make your home safe for you and the baby
 - Plan for the extra tiredness that comes with being a parent if that might trigger your seizures
 - Explain to your child what epilepsy is and what to do if you have a seizure

Rebecca, 16



Go and enjoy your life and spread the word that epilepsy is a real issue that people need to know.

Rebecca