

Enabling social support for people with epilepsy

A TOOLKIT FOR COMMISSIONERS





Epilepsy Connections supports people with epilepsy and their families in Forth Valley and Greater Glasgow. We run a variety of projects and services within the Forth Valley and Greater Glasgow & Clyde Health Board areas, offering information, advice and support to people with epilepsy, their families, friends and carers and the professionals working with them.



Epilepsy Scotland has been providing support for people living with epilepsy in Scotland since 1954. In that time, we have never rested on our laurels, shied away from challenge or stopped looking for other ways of improving the lives of those we represent; people with the diagnosis of epilepsy as well as their families, schools, colleagues and communities.



Iriss is a charity that works with people, workers and organisations in social work and social care to help them use knowledge and innovation to make positive change happen. Iriss has supported social work and social care in Scotland since 2008 bringing skills and expertise from a range of disciplines to development work.



Lanarkshire Epilepsy was formed in 2011. It's aims were to provide support for all people living with epilepsy in Lanarkshire, increase public awareness and understanding of epilepsy, and to help to overcome the ignorance and fear that still surrounds epilepsy. Lanarkshire Epilepsy was disbanded in 2024 due to a lack of funding.

QUARRIERS

Quarriers believes in helping people to live the lives they choose. We provide practical support to help people learn, grow and be all they can be. Our vision is for people to have greater independence, be included in their communities, and have choice and control over their support. We believe in challenging stigma and inequality, and giving people the opportunity to thrive.

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1. Foreword



As the National Clinical Director within the Scottish Government, I have been privileged to have worked across a variety of healthcare settings and have been especially supportive of programmes of reform which prioritise collaboration and which make best use of increasingly scarce resources to drive improvements in patient care. The development of a national collaborative to enhance support for people with epilepsy is one such example.

The evidence tells us that people whose epilepsy is not controlled will have poorer outcomes than the rest of the population – they are less likely to have a job, more likely to be socially isolated, more likely to have mental health problems and will usually have higher mortality. However, where people can access a supportive environment, together with the appropriate clinical input, then outcomes will improve.

That is why this resource is so helpful. It outlines the case for providing more holistic care and support and encourages partnership between Health Boards and Local Authorities to work with the rich tapestry of third sector providers to deliver holistic support for people with epilepsy. Service provision in Scotland just now is uneven – but if we can encourage collective action, we can ensure that everyone with epilepsy in Scotland will receive the right support at the right time.

Jason Leitch,

National Clinical Director of The Scottish Government

2. Background

Quarriers, Epilepsy Connections and Epilepsy Scotland provide various types of support and advice to people in Scotland with an epilepsy diagnosis. Through their work they recognise the fragmented nature of support for people with epilepsy across geographies and professional disciplines.

Social support and outreach for people with epilepsy is not available in all areas and where it is available, services are often fragile due to short term funding and the lack of a long-term strategic approach. As a result, the experience of accessing this type of support is a 'postcode lottery', it is highly variable in availability, with some people receiving excellent support from existing services while others struggle to access support services at all.

With funding from the Scottish Government, Quarriers, Epilepsy Connections, Epilepsy Scotland and Lanarkshire Epilepsy worked with Iriss to develop a national approach for commissioners to improve the availability of social support for people with an epilepsy diagnosis.

To create this resource Iriss gathered qualitative data to complement published data and evidence about the impact of social support on people with epilepsy. Iriss attended group meetings hosted by Epilepsy Connections and Epilepsy Scotland to engage members in focus group discussions. Practitioners were invited to share their views at an online focus group which maximised participation from across Scotland. Commissioners were invited to one-to-one interviews to share their perspectives on the current commissioning context.

The experiences and perspectives of those who took part in focus groups and interviews have provided invaluable support and knowledge to the creation of this resource. Thank you to all who contributed.

3. Introduction and context

3.1 PURPOSE OF THIS RESOURCE

This resource is a tool to assist evidence-informed commissioning of sustainable social support for epilepsy that meets local need and contributes to national outcomes. There is work to do to create the conditions and social support options for people with epilepsy regardless of where they live in Scotland.

The aim of the resource is to:

- Improve understanding about epilepsy in Scotland and awareness of the impact it has on people's lives
- Highlight the difference social support makes to health and wellbeing outcomes
- Show how investing in social support can effectively complement and supplement clinical care provided by the NHS
- Provide commissioners with a structure and set of key questions to support action planning.

3.2 HOW DOES EPILEPSY IMPACT PEOPLE'S LIVES?

58,000 people in Scotland are living with epilepsy (Scottish Government, 2022).¹ This can bring challenges beyond seizures for individuals. The various impacts epilepsy has, interact with each other, resulting in complex and layered difficulties for some people.

Mental health

Recent research in the USA found that approximately 24% of people² with epilepsy had been diagnosed with a mental health disorder compared with 11% of those without epilepsy.

54% of respondents to a Scottish survey said that epilepsy had a significant impact on their mental health.³ 46% said it causes them anxiety.⁴

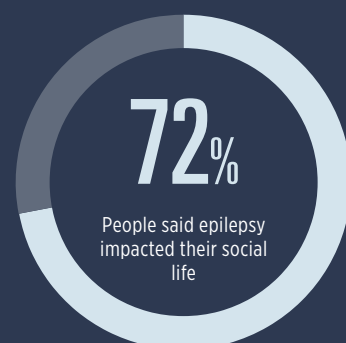
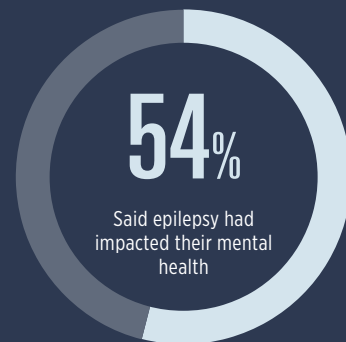
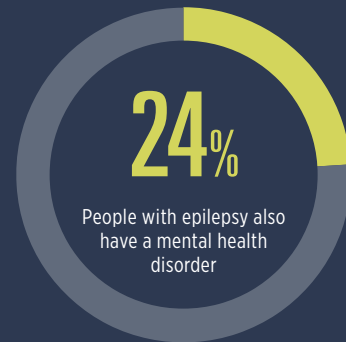
78% of Epilepsy Scotland's Youth Group members said that the support they have received has helped with their self-esteem or confidence.⁵

"Epilepsy Connections' Counsellor has really helped me cope with my mental health. I was always angry and frustrated about my epilepsy and asked "why me?" While I still get frustrated with seizures she has helped me learn coping strategies and I find it easier to stay positive and cope with my anger now." (Epilepsy Connections, 2023)⁶

Isolation

72% of people said that epilepsy impacts their social life.⁷

"Epilepsy has made me social phobic; it prevents me from interacting with people as I am ashamed of having epilepsy." (Epilepsy Connections)⁸



Stigma/judgement

People with epilepsy often worry about how they will be perceived if they have a seizure when they are out, alone, in the community:

“See when I go to Tesco or Asda for my shopping on my own, see when I get to that door I start to kind of shudder a wee bit. Because I think to myself ‘God am I going to be okay in here myself?’ ... I try not to look at anybody in the face and just get what I need... I sigh with relief because I think ‘thank god, I’ve done it. I haven’t had a seizure in front of people...”

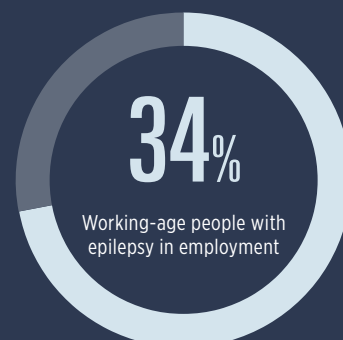
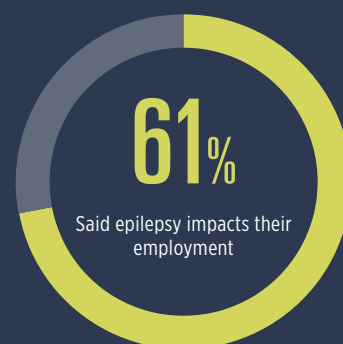
“They don’t know because they lack the education of how to support someone who is epileptic and when they see you taking, or not being well, they think that you have taken drugs. Sometimes they will just leave you...”

Employment

Epilepsy can make it more difficult for individuals to find or remain in paid employment. 48% of respondents to an Epilepsy Scotland survey were not in employment and 61% said their epilepsy impacts their employment.⁹

Only 34% of working-age people with epilepsy are in employment (Office for National Statistics, 2022)¹⁰

“They can say it’s about something else.. she had the seizure at work... she was getting 30-35 hours a week, suddenly the next week she only got four hours...”
— Practitioner



Physical health

People with epilepsy often have co-morbidities. A European study of people with epilepsy found they had higher rates of high cholesterol, Type 1 diabetes, osteoporosis and migraine than control groups.¹¹

Mood and anxiety disorders are also common among people with epilepsy.¹²

“Misdiagnosis, debilitating side effects of ASM (anti-seizure medication), adverse interactions of medicines for other health conditions and significant injuries including burns and fractures from uncontrolled seizures can be common in people with epilepsy, resulting in poor physical health and if not treated can put people at risk of further physical health conditions.” — William Quarrier Scottish Epilepsy Centre Clinician

Cognition and memory

Some impairment in cognitive function and memory is reported by people with epilepsy.¹³

“Referring people for social support... people are already needing help managing their bank accounts on a daily or weekly basis, I’m thinking of somebody who has been subject to fraud in the past, their memory is not good enough to keep on top of what’s going on...”
— Practitioner

“I think things like... memory. Things like that, people wouldn’t know that’s such a big thing. That’s something that pretty much everyone we work with mentions as like a big issue. The side effects of the medication, and just the impact of seizures over time...” — Practitioner

Sleep

Poor sleep and sleepiness through the day are common among people with epilepsy.¹⁴

One third of people with epilepsy experience sleep disturbance.¹⁵

“Some people have very specific seizure triggers, and to some people it’s a brand new conversation that you’re not entirely helpless, that you might have a seizure trigger. Common seizure triggers are lack of sleep, stress, things like that... We have in the past run specific sleep sessions just to help people understand the importance of sleep...”
— Practitioner

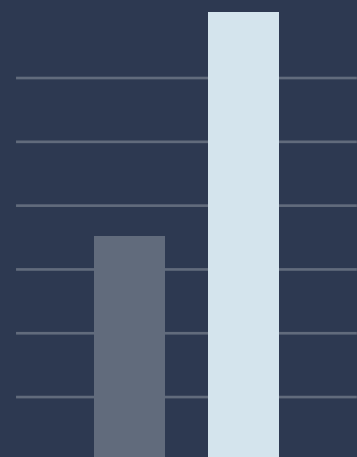


One third of people with epilepsy experience sleep disturbance

Deprivation/poverty

People in the most socially deprived areas in the UK are twice as likely to have epilepsy as those in the least socially deprived areas.¹⁶

“Quite often a parent has to give up work, and if it’s a single parent then it’s really dire. And then there’s the challenges with the benefits system... it now takes a very long time to process a child disability payment application. And although it’s back dated, you need the money now... I think it’s just sheer exhaustion for families when you have to hold it all together.” — Practitioner



Those in socially deprived areas twice as likely to have epilepsy

3.3 WHAT IS THE VISION FOR SUPPORT FOR EPILEPSY IN SCOTLAND?

There is a vision that support for people with epilepsy should be developed further so that:

- People with epilepsy can access holistic and integrated care, support and information, which enables them to understand their condition and access relevant resources
- People with epilepsy are empowered to be involved in decisions affecting them in the context of their wishes, wider wellbeing and circumstances
- People with epilepsy are enabled to be active citizens, achieving their potential, and flourishing as individuals.

Holistic and integrated care and support for epilepsy should be a combination of clinical care and social support that takes place outwith clinical settings. The unique contributions made by specialist primary care, specialist secondary care and social support are all needed. At present social support is under-developed across Scotland. It is essential that it is resourced well to ensure that there is holistic and integrated care.



Figure 1: The Wheel of Support

Five principles have been co-developed with supported people and social support practitioners to underpin and enable the vision set out above. The principles focus on creating social support for people living with epilepsy in Scotland that is:

- Available across all regions of Scotland
- Well connected to NHS clinical support
- Sustainably funded and resourced
- Contributing to making national policy and outcomes a reality
- Built on expertise through living experience and practice knowledge.

3.4 DEFINITION OF SOCIAL SUPPORT

Social support for people with epilepsy focuses on providing a person with resources and knowledge and developing skills and confidence to live well and safely with epilepsy and self manage their condition. Social support is delivered in a variety of ways, by skilled and experienced professionals, including third sector providers. Social support can include, but is not limited to:

- Information, advice and guidance from a specialist epilepsy support worker
- Peer support meetings and activities, hosted by a support worker
- Epilepsy self management courses, delivered online or in person
- One-to-one support from a support worker, or through phonenumber services
- In person or online counselling accessed through an epilepsy support organisation.

For ease of reading, throughout this document, social support is used as the umbrella term to refer to these services.

Social support and clinical support are separate but should be complementary to each other with points of intersection as part of a joined-up approach to supporting people to live well with this neurological condition. Social support recognises that epilepsy has an impact on an individual beyond the occurrence of seizures. Work by Charyton and others (2009)¹⁷ suggests that health related quality of life is negatively impacted for people with epilepsy who experienced a lack of social support; as social support can counter isolation and protect against the challenges accompanying a chronic illness. Similarly, Kılınç and others (2020)¹⁸ highlight that people with epilepsy could benefit from psychosocial support that considers the impact the condition has on their lives beyond seizures.

3.5 WHAT IS EPILEPSY?

Epilepsy is one of the most common serious neurological conditions in the world. Epilepsy can affect anyone.

It is often defined as the tendency to have repeated seizures which start in the brain. Seizures may take a number of different forms which can have implications for the person with epilepsy as not all types of seizure are well known or recognisable.

No two people experience epilepsy in exactly the same way. For one person, epilepsy can mean complete seizure control on medication. For another person it can mean uncontrolled and frequent seizures despite medication.

There are multiple possible causes of epilepsy (Epilepsy Scotland, 2024).¹⁹ These include:

- An identifiable cause, such as an acquired brain injury;
- Developing epilepsy following a diagnosis of dementia;
- Genetic causes, such as if the brain has not formed properly in the womb as a result of a genetic fault. People with Down's syndrome, autism or with learning disabilities are statistically more likely to have epilepsy.

Find out more about epilepsy at Epilepsy Scotland and Epilepsy Connections.

3.6 HOW PREVALENT IS EPILEPSY IN SCOTLAND?

Around 58,000 people in Scotland have epilepsy, that is 1 in 97, with diagnoses being more common in childhood and later life (Scottish Government, 2022).²⁰ A study across the UK nations (Wigglesworth and others, 2023)²¹ estimated that there are 49 new cases of epilepsy diagnosed in Scotland every day (higher than England with 38 new cases a year).

The same study showed a connection between increased prevalence of epilepsy in areas of deprivation; people living in deprived areas are a third more likely to have epilepsy than those living in the least deprived areas. This is something that previous studies by other researchers have also shown.

4. The landscape of social support

This section sets out the landscape of social support for epilepsy in Scotland, focusing on geography, need and policy context.



4.1 WHERE IS THERE SOCIAL SUPPORT FOR EPILEPSY IN SCOTLAND?

Despite the prevalence of epilepsy across Scotland, in-person social support services for adults are only funded across four health board areas and the support is provided by third sector organisations; Quarriers, Epilepsy Connections and Epilepsy Scotland. Specialist epilepsy youth groups are facilitated in Edinburgh and Glasgow by Epilepsy Scotland. A telephone helpline with a national remit and phone Check-In service are also provided by Epilepsy Scotland.

Areas where social support for adults with epilepsy is currently funded (2024): Grampian, Glasgow City and Clyde, Forth Valley, Fife.

As the map above shows, there are few areas in Scotland where in-person social support is available, access is a postcode lottery. In part, this is because social support is currently funded by a range of public bodies, including:

- NHS Boards
- Health and Social Care Partnerships
- Community Planning Partnerships
- Local Authorities

As no one public body has ownership of commissioning support services, the commissioning process can be short-term, disjointed and lacking strategic planning. Some services in Scotland are commissioned by a combination of these bodies; but the bodies do not typically share an arrangement or strategic plan. This makes it difficult for providers to sustain and grow high quality services, as they have to build their service from funding sources that are disconnected from one another.

4.2 UNMET NEED FOR SOCIAL SUPPORT

Support workers are regularly contacted by people outwith their service boundaries and are often frustrated that they do not have a point of onward referral as no comparative service operates in the person's locality.

It's quite frustrating for us as well to maybe not have workers in all the areas that we do get people referred from ... we've only got a small amount of hours to work with people. But there's a lot of people from [other areas] who need support. — Practitioner

Even where services are operational, practitioners know they are not reaching everyone with epilepsy in their area who is in need of support.

Unmet need is even higher in areas where there is no community-based epilepsy support of any kind – be that social or clinical support.

Epilepsy Specialist Nurses (ESNs) are under-resourced nationally with some areas facing long term recruitment challenges into posts. ESNs are a bridge between a patient and their neurologist and this role can reduce pressure on acute services. Research by Epilepsy Scotland (2022)²² showed that the ESN workforce had reduced by an estimated 15% on the previous year with the impact of overloading caseloads for those who are in post. Resourcing of these posts has not recovered since.

In many areas of Scotland the lack of social support or a specialist nurse means that people living with epilepsy have no access to the preventative care and support that either of these services can provide

Social support and specialist nursing care are not interchangeable – these services are complementary as shown in the graphic on page 7. An integrated approach to commissioning epilepsy support could go some way to creating better conditions and make this a reality in local areas.

4.3 THE POLICY CONTEXT FOR CHANGE

The urgent need to improve how people with epilepsy are supported is underpinned by the Scottish Government Neurological care and support: framework for action 2020-2025.²³ This sets out 17 commitments from the Scottish Government for future improvement and implementation of support for people with neurological conditions including epilepsy. These commitments sit under five key outcomes linked to national Health and Social Care Standards²⁴ and the National Performance Framework.²⁵

1. Ensure people with neurological conditions are partners in their care and support
2. Improve the provision of coordinated health and social care and support for people with neurological conditions
3. Ensure high standards of effective, person-centred, and safe care and support
4. Ensure equitable and timely access to care and support across Scotland
5. Build a sustainable neurological workforce fit for the future

Later in this toolkit we show where aims and commitments of the framework can be demonstrated through outcomes-focused commissioning.

More widely, the landscape of social care and support commissioning in Scotland is changing, driven by the ambition set out in the 2021

Independent Review of Adult Social Care²⁶ ('Feeley review') that called for structural reform of care and support to make it enabling and equitable for supported people and workers. The direction of travel is towards fully integrated care and support, with the removal of unwarranted regional variation in services, and parity in conditions amongst public, private and third sector members of the workforce. As a means to achieving these outcomes, the Review points to reforming commissioning and procurement approaches (ethical commissioning) and the potential creation of a National Care Service.

In 2024, the Scottish Government is further developing an ethical commissioning outcomes framework which will provide structure and clarity for Health and Social Care Partnerships (HSCPs) to develop and implement outcomes-focused and integrated commissioning approaches that incorporate Fair Work priorities. The development of the ethical commissioning framework by the Scottish Government aligns with the voluntary sector Fair Funding agenda²⁷ that highlights the need for multi-year, sustainable funding practices for third sector organisations – many of which are integral to the provision of social care and support.

Practitioners have shared their frustrations with some of the current models of funding for epilepsy social support that do not allow them to plan for the future, or build a service that is sustainable and resilient with capacity to meet need over the longer term:

...pots of money for specific pieces of work... so while that gives us maybe, let's pull £10,000 out the air... for a six month or a year's piece of work. Essentially that gives us more work to do, but without any real forward thinking. [We need] money that gives us the security that the service needs. That said we have been able to do some nice meaningful pieces of work... but long term it's unsatisfactory. — Practitioner

It is an opportunity now to start developing local culture, processes and systems needed to maximise the return on workforce and financial resources and embed more sustainable support. For example, improved integration of mental health and social care commissioning would have potential to directly improve outcomes over the short and longer terms for people living with epilepsy (as well as for people with other neurological conditions). The next section of this toolkit goes into more detail about the impacts of taking an integrated approach to commissioning social support for people living with epilepsy.

5. Why commission social support?

There's always a medical issue up front with side effects of medication, medical appointments ... But it's much bigger, much bigger than that. The mental health struggles, the memory challenges ... the medical is just the tip of the iceberg really. — Practitioner

Commissioning social support for people with epilepsy can make a huge difference to people's quality of life and wellbeing. Social support is varied, and can support people in a range of ways and with different parts of their life.

In addition to improving the quality of life for people with epilepsy; local commissioning action to improve personal outcomes for people with epilepsy is in line with the local and national outcomes for health and wellbeing in Scotland. Moving to an outcomes-focused approach to commissioning support for epilepsy would integrate local plans with the longer term ambition in Scotland for care and support that is preventative and enables independent and active living.

Commissioning social support reaches further than improving the personal outcomes for people with epilepsy. Social support complements and augments the support provided from clinical interventions. Studies (Lu and Elliot, 2011)²⁸ suggest that even alongside medication to control seizures, people's health and wellbeing remains negatively impacted in the absence of social support. While social support and clinical care have clear separate functions; each complements and improves the effectiveness of the other.

Furthermore, social support can act as a preventative measure to people reaching crisis point, at which stage they often require intense intervention. Spending on social support can divert spend from crisis

interventions and avoid spend on more costly interventions needed once someone's condition has deteriorated. Recent work related to early intervention for young people with epilepsy has demonstrated how early psychological screening can be more cost effective and prevent Child and Adolescent Mental Health Services (CAMHS) referrals at a later stage (Healthcare Improvement Scotland, 2022).²⁹

5.1 SOCIAL SUPPORT MAKES A DIFFERENCE TO PEOPLE'S PERSONAL OUTCOMES

Supported people have spoken about how social support makes a difference to their lives:

1 SUPPORT PROVIDES SAFE SPACE

Attending groups brings people together, with a shared experience of having epilepsy. Everyone in the room can relate to this, which engenders a sense of safety - both emotional safety, and that is a practically safe place should someone have a seizure.

“ It makes you feel more comfortable, you know people are similar to yourself, see what you're facing. ”

2 PEOPLE ARE SEEN AS INDIVIDUALS

Everyone has epilepsy in common at support groups. This allows individuals to be themselves, as they are safe in the knowledge that the people around them understand. People could find freedom in this to be themselves.

“ We all have epilepsy but we don't just sit here and talk about epilepsy. ”

3 THERE IS SPACE TO BUILD CONFIDENCE

Being in an environment that is stigma free, allows people to build their confidence. Experiencing judgement from others, or feeling that epilepsy is negatively impacting their life can erode people's confidence. Group settings offer the opportunity to rebuild this.

“ Well it has helped my confidence, meeting other people with epilepsy... when I used to go out with my mum, or my cousins or that in the town, people would look at you like you're on drugs. ”

4 OPPORTUNITIES TO GROW A SOCIAL NETWORK

Meeting in groups allows people to build authentic relationships, and to share information with each other, about what else has helped them. Some groups organise visits to local amenities, and support workers can share information about other offers in the community.

“ Through this group I heard about a mental health group... started meeting up regularly with some boys from there. ”

5 ACCESS TO INFORMATION AND GUIDANCE

Support workers can support beyond facilitating group meets. People with epilepsy might also find that they have issues with their housing, social security, education and employment. Being linked in with social support allows workers to provide assistance in these areas.

“ We can phone, ‘I’ve got a problem with my housing... and I don’t understand this, I’ve got a letter’ [workers] are free to come to your house and say ‘let us see that letter that caused you to worry’... ”

6 OPPORTUNITY FOR INFORMAL AND FORMAL LEARNING

People can gain knowledge about how to manage their condition, both informally, through talking with one another; and through formal information that organisations can provide. Guest speakers, such as the local epilepsy specialist nurse, or other support providers, can attend to share the wider support available.

“ ...you’re more relaxed and you can hear other peoples stories as well... You can learn from them and they can learn from you about different ways and I think that’s a really important thing. ”

7 IT CAN REACH PEOPLE ACROSS SCOTLAND

Remote support, provided by phone call or video call can be important for those unable to access services in person; or to dovetail with in-person support. It can widen access to support for people in remote and rural locations, and can have a very important role in providing support to someone in a crisis situation.

“ Thank you so much for this support. I feel so much less anxious now and having the weekly check in was invaluable and really helped me feel that epilepsy wasn’t ruling my life. ”

5.2 THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND CLINICAL CARE

Social support has a complementary and supplementary role to clinical care, providing a place for people to learn more about epilepsy, contextualise and reinforce the information they've been given at medical appointments. Social support has the potential to prevent people with epilepsy experiencing a deterioration in their condition and the subsequent impacts this has on their longer term health and need to rely on other services.

Sustainable resourcing of both clinical and social support makes for a robust provision of support for people with epilepsy.

Social support complements and supplements clinical input...

Clinical staff and support staff have different functions in a person's life. However, these roles are complementary and offer a more robust, holistic support system for people with epilepsy than one type of support alone can achieve.

“...so I think areas where they maybe don't have much epilepsy specialist nurse provision or then an epilepsy specialist support service, would really be missing out I would think... when you've got both, ESN and the support service it seems to make a big difference.”
— Practitioner

“...being that bridge between an epilepsy diagnosis from neurology or maybe being in hospital and waiting for an appointment with epilepsy specialist nurses, just us sort of being there as someone to maybe talk through what they've already been told and give them a little bit more information... maybe not remembering exactly what's been said at the appointment.”
— Practitioner

Support groups and practitioners can advise people between appointments, or provide a place to debrief afterwards.

Practitioners can support people to prepare for appointments with medical professionals, in order that people can make the most of the time they have with clinicians, and get the information they need.

“So we do things like... getting the best out of your health professional, trying to prep people for when they go into the appointments so that they know like, what’s good.”
— Practitioner

Practitioners can clarify information given to people at appointments, as they have more time and space to spend with people than during a designated appointment time.

“And especially when it’s a new diagnosis and it can be a real shock for someone, and they have their half hour appointment with the specialist, and then there’s maybe lots of questions they forgot to ask... [Being referred to social support] means you can just give them a bit more advice...”
— Practitioner

Social support can continue to provide information and support to people who have some time out of clinical support, for example because their seizures are well controlled. Social support mechanisms can also support people back into clinical pathways, for example supporting people to reach out to GPs to be re-referred to a neurologist.

“...even if someone gets to a point maybe where their seizures are relatively well controlled and they’re managing medication, and they’re managing the side effects of the medication, then it can be that they are discharged from neurology services with a sort of open end that you can always be referred back in if something were to change...” — Practitioner

“I wanted to understand more about different future options, and mentally understand [epilepsy] for myself... I don’t have [a clinician] now, because I’ve been seizure free, so I don’t have one...”
— Supported person

Social support can be preventative...

Social support can provide the necessary input to support someone out of a challenging position. This allows people to better manage their epilepsy, and make positive changes in their lives.

“When I got that first call from you I felt so overwhelmed I was almost paralysed. I had no support and felt invisible. That first call was like someone throwing me a life belt and slowly but surely I’m getting closer to the shore: to where I can feel the ground beneath my feet.” – Supported person

“Epilepsy is the root of the problem that then just grows and causes all these other problems. If people could just see that, that would be really, really helpful for folk like us, who are trying to support people who have got these complex needs.”
– Practitioner

Support for epilepsy prevents the condition from having a spillover effect, and negatively impacting other areas of peoples’ lives. Social support can prevent people from reaching a point where they find it challenging to manage their condition, and their life is negatively impacted.

Self management courses can support people to learn more about their condition, and empower them to be partners in their care.

“It was quite in depth as well, what is epilepsy, what triggers your seizures...”
– Practitioner

“...it was a three year funded project called living well with epilepsy... it was to run six week epilepsy education workshops ... That was a great project that gave us the opportunity to bring a local community pharmacist along, the epilepsy specialist nurse along, and it just gave access to a lot of information...”
– Practitioner

People can learn about and share information with each other, that supports them to be able to manage their condition.

“...but I suppose when you come along to groups like this, or access support, there’s a bit more of an opportunity to be like ‘right, what are the chances of my medication working?’ or ‘what lifestyle stuff can I do to improve my chances of seizure control?’”
— Supported person

“I think it’s fair to say that most of the people we support are not seizure free... I think with support these are people that with support can lead independent, meaningful lives. But without that support then it’s very, very difficult... these are people who, with support, can look at things like further education, that can be supported to get employment, or continue to be employed. And with that then they’ve got financial support rather than the poverty that we see a lot of people with epilepsy living in.” — Practitioner

Support with benefits and income maximisation, housing, attending appointments, and other activities can better enable people to participate in their local communities. This can also contribute to reducing reliance on other services or support people might typically need to access when facing difficulties or in crisis, such as foodbanks.

Practitioners can support people to approach their employer about their condition. This can support people to maintain employment, or re-enter the job market.

“You get the other camp of people who really want to work and they encounter so many barriers when they go out job hunting. There are some really good examples out there... But there are also a lot of employers out there who hear epilepsy and then they come up with whatever excuse.”
— Practitioner

6. Journey to action: effective commissioning of support

6.1 AN EFFECTIVE APPROACH TO COMMISSIONING

An effective commissioning process has a role to play in creating the conditions for integrated support for people with epilepsy. Effective commissioning responds strategically to population need and develops robust partnership arrangements to support joint discussion about how best to meet that need and what funding arrangements need to be in place. Examples of funding streams that have been used to support service development include:

- NHS endowment funds
- Community Planning Partnership grant funding awards
- Health and Social Care Partnership / Local Authority grant funding awards and tendered service provision.

Partnership arrangements have the potential to be a solution to the currently disjointed commissioning of epilepsy services. Some areas have adopted a regional approach, combining the efforts of NHS Boards and constituent HSCPs. This can often provide more comprehensive cover across the region, with fair access to support. Lead commissioner arrangements (where a single HSCP takes the lead for the coordination of the commissioning process on behalf of other HSCPs and the Health Board) are an effective way of supporting this work.

There is work to do to create the conditions and social support options for people with epilepsy regardless of where they live in Scotland. A detailed version of the commissioning cycle and a set of key questions to support action planning are set out below in sections 6.2 and 6.3. Together these are offered as a structure that commissioners could use to gather relevant information and build capacity at a local level.

6.2 THE COMMISSIONING CYCLE

The commissioning cycle (figure 2) was developed in 2018 by the Coalition of Care and Support Providers in Scotland (CCPS) and adapted by Iriss in 2022 as a support tool for putting the principles of Ethical Commissioning³⁰ into practice. It is a useful tool for thinking about adult social care planning, extending a Plan Do Study Act (PDSA) action learning or improvement cycle into a more nuanced process that centralises supported people in the planning and purchasing process.

Here commissioning is visualised as a wheel, or cycle, with each step flowing neatly to the next. However, we know that in reality these stages are likely to be happening simultaneously across different areas, and your starting point may depend on your role

The cycle focuses on relationship building and working together to consider if people have the right support available to choose from. We can apply ethical commissioning principles and practices to each stage of this cycle to help examine where change is possible, and in this case specifically focus on developing an integrated support pathway for people living with epilepsy that includes social support alongside clinical care.

The key stages of the cycle are **build, gather, analyse, plan, do, review**, and are described in figure 2 on the following page.

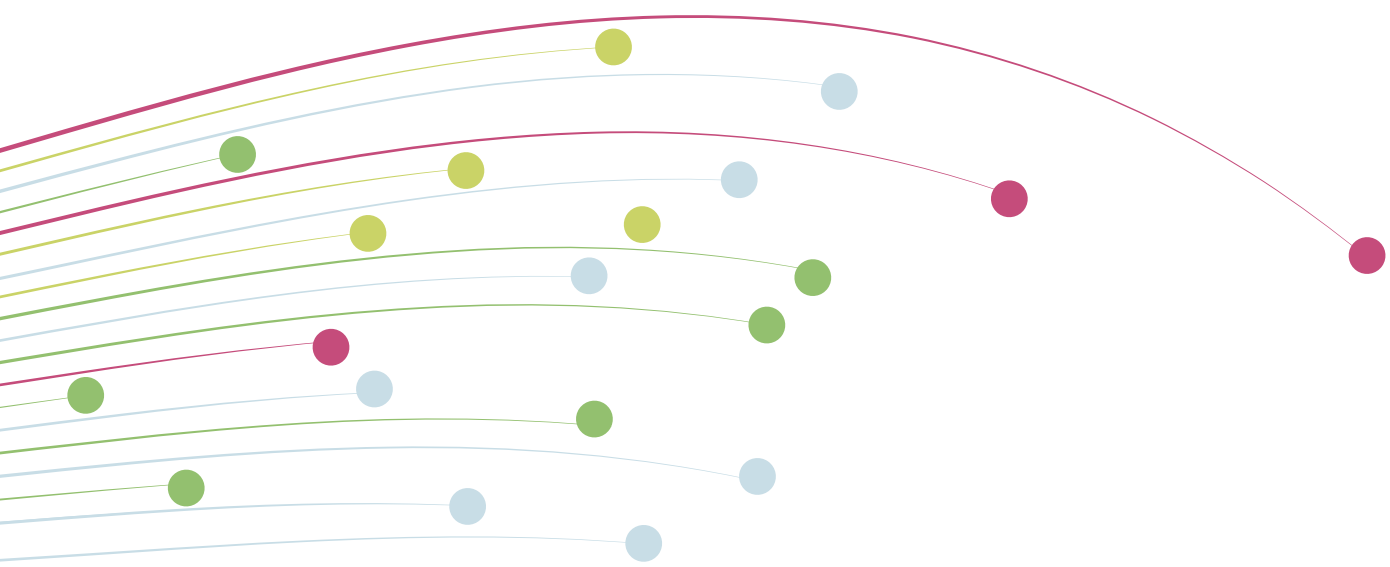




Figure 2: The commissioning cycle

6.3 KEY QUESTIONS TO SUPPORT ACTION PLANNING

Stage	Description	Key questions to support action planning
BUILD	<p>Connect with local and national epilepsy organisations, epilepsy specialists, NHS contacts and relevant third sector organisations, in your area.</p> <p>Build working relationships to help you.</p>	<ul style="list-style-type: none"> • Is there a clear pathway of support, which provides integrated care for people with epilepsy across specialist NHS care, primary care and social care? • If not: <ul style="list-style-type: none"> - Who are the organisations and people who can assist me? - Who do I have a relationship with already who could link me with the right people?
GATHER	<p>Identify any data gaps in your area about the numbers of people with epilepsy, and the support they access.</p> <p>Undertake a needs analysis to understand both needs that are met and unmet for people.</p>	<ul style="list-style-type: none"> • How well defined is the local population of people with epilepsy? • Has there been a mapping exercise to define what support is available locally across specialist NHS care, primary care and social care? • What are my sources of information and data? How reliable are these? • How can I address any gaps or duplications in my knowledge base? Are there third sector organisations who can assist? • Who can I connect with to share data and learn from each other?
ANALYSE	<p>With practitioners, people with epilepsy and other key stakeholders, undertake a collaborative assessment of what is needed from social support.</p>	<ul style="list-style-type: none"> • What is most important to people accessing social support for epilepsy, now and in the future, in my local area? • How do assumptions about what support 'should' look like, and how it is provided, match with what people say they want from support? • Are we seeing 'workarounds' that providers are having to set up in order to provide good support that could be eliminated by having a more flexible or bespoke purchasing model? • In the absence of existing support, could providers operating elsewhere contribute their knowledge and expertise to the development of good support?

Stage	Description	Key questions to support action planning
PLAN	Identify the funding channels needed to ensure that support is sustainably resourced and funded. Plan support that is connected with the local NHS, and clinical pathways.	<ul style="list-style-type: none"> • What models of funding could be used to do this collaboratively and with shared accountability? • Will our proposed approach offer sustainable provision for supported people and fair, sustainable work for providers? If not, why not? What is in our gift at a local level to change or make steps towards improving this?
DO	Implement the funding and delivery plan for a support service for people with epilepsy.	<ul style="list-style-type: none"> • How will we know if the support is high quality, person centred and meeting the needs of people with epilepsy? • What measures and approaches will we use to gather evidence about what works in the support given? • What measures will we use to understand if our collaborative working is effective and what factors help or hinder this? • How does this work fit with local strategic commissioning plans?
REVIEW	Evaluate if the service is working for supported people and providers; and if the support is assisting in meeting the commitments set out in the neurological framework.	<ul style="list-style-type: none"> • Is this working for supported people? Is this working for providers? Is this working for commissioners? How do I know this? • What is sustainable, and what needs further review, disinvestment or change? • What does this contribute to the implementation of strategic planning in my locality and to the implementation of the neurological framework?

7. Outcomes-based commissioning

7.1 ABOUT OUTCOMES-BASED COMMISSIONING

Taking an outcomes-based approach to commissioning and contracting can be an enabler of improved integration between health and care services to support people living with epilepsy. Focusing on outcomes as part of contract monitoring can provide a rich source of relevant data about what works and local unmet need, as well as contributing to measuring progress on national aims and outcomes, such as those of the Neurological care and support: framework for Action 2020-2025³¹ or national Health and Wellbeing Outcomes.³² Taking an outcomes approach aligns with the principles of ethical and person-led commissioning and service design that is embedded in the Independent Review of Adult Social Care and national Health and Social Care Standards.

Outcomes-based commissioning and contracting shifts the focus from outputs (eg number of delivery hours stipulated in a contract, or specific activities undertaken by workers) to personal outcomes of people being supported. For example...

Output based: ‘We will provide 12 hours of support a week to ensure Ali’s health remains stable’.

Outcome-based: ‘Ali’s health remains stable.’

(CCPS, Commissioning for Outcomes, 2022, p.4)

Some personal outcomes, eg a person’s health remaining stable or improving, can be transposed to local population level through aggregating outcomes data gathered by support providers, with potential to link

this to data from NHS clinical partners for more detailed insights and understanding of the impact of both clinical and social care and support for people living with epilepsy.

An accessible and practical guide to outcomes-based commissioning:CCPS Commissioning for Outcomes (2022).³³

7.2 CONNECTING PERSONAL TO LOCAL AND NATIONAL OUTCOMES

The table below shows a set of potential outcomes that could be achieved at personal, local and national levels through the implementation of an integrated pathway for epilepsy support that includes social support as a core component.

These suggested personal, local and national level outcomes are also in harmony with Health and Social Care Standards and could readily be incorporated into Local Plans.

Personal/ individual outcomes	Local	National
<ul style="list-style-type: none"> • Improved access to social support. • Increased knowledge about what support for epilepsy is available. • Increased access to resources about how to manage epilepsy. • More confidence in living independently. • Better enabled to participate in employment, learning and/ or other social activities. 	<ul style="list-style-type: none"> • Increased proportion of people with epilepsy are enabled to manage their condition well. • Fewer crisis interventions or NHS crisis visits directly caused by epilepsy. • Care and support planning is better informed by relevant data about the need for epilepsy support in the local population. 	<ul style="list-style-type: none"> • Social support for people with epilepsy is more equitably available across Scotland. • There is less stigma and more informed understanding of epilepsy in Scotland. • The population of people with epilepsy in Scotland are better enabled to engage in employment, learning and leisure activities. • The population of people with epilepsy in Scotland have improved health and wellbeing outcomes.

Table: Personal, local and national outcomes from commissioning social support for epilepsy

Aims from the Framework alongside specific commitments which could be evidenced or developed through commissioning of social support are set out in the panel below.

Neurological care and support: framework for Action 2020-25

Abridged aims and key commitments that could be evidenced or developed through commissioning social support for people with epilepsy

A. Ensure people with neurological conditions are partners in their care and support

Commitment 1: We will support shared decision making and personalised models of care and support, including access to supported self-management where appropriate.

B. Improve the provision of coordinated health and social care and support for people with neurological conditions

Commitment 4: We will ensure that the legislation, policy and guidance that Integration Authorities and the NHS use when planning and commissioning services are designed to support consistent, timely and appropriate provision of care and support for people with neurological conditions.

C. Ensure high standards of effective, person-centred, and safe care and support

Commitment 11: We will promote and support the implementation of the Health and Social Care Standards 2018 and Healthcare Improvement Scotland General Standards for Neurological Care and Support 2019.

Commitment 12: We will work with NHS Information Services Division and others to ensure a cohesive approach to capturing the needs of people with a neurological condition that will:

- Improve the recording of neurological conditions in people's routine health and care records, so that they are visible to appropriate services;
- Enable more accurate population-level estimates of the prevalence of neurological conditions to inform other data analysis; and support the development of systems and processes for service planning and workforce development, based on these improved prevalence estimates.

D. Ensure equitable and timely access to care and support across Scotland

Commitment 14: We will seek to improve access to healthcare and support by working with the Scottish Access Collaborative for Neurology and other partners to develop nationally agreed, regionally and locally applied guidelines for health services and referral pathways for neurological conditions.

8. Acknowledgements and contact

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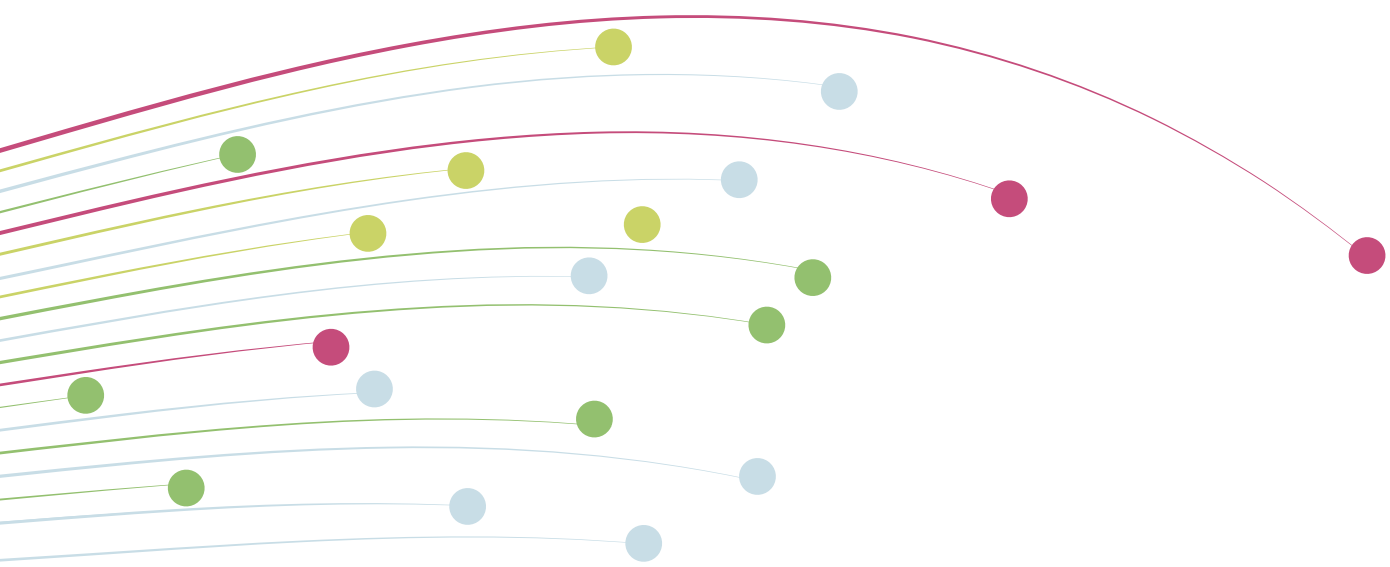
To follow up on anything you've read here contact a lead partner:

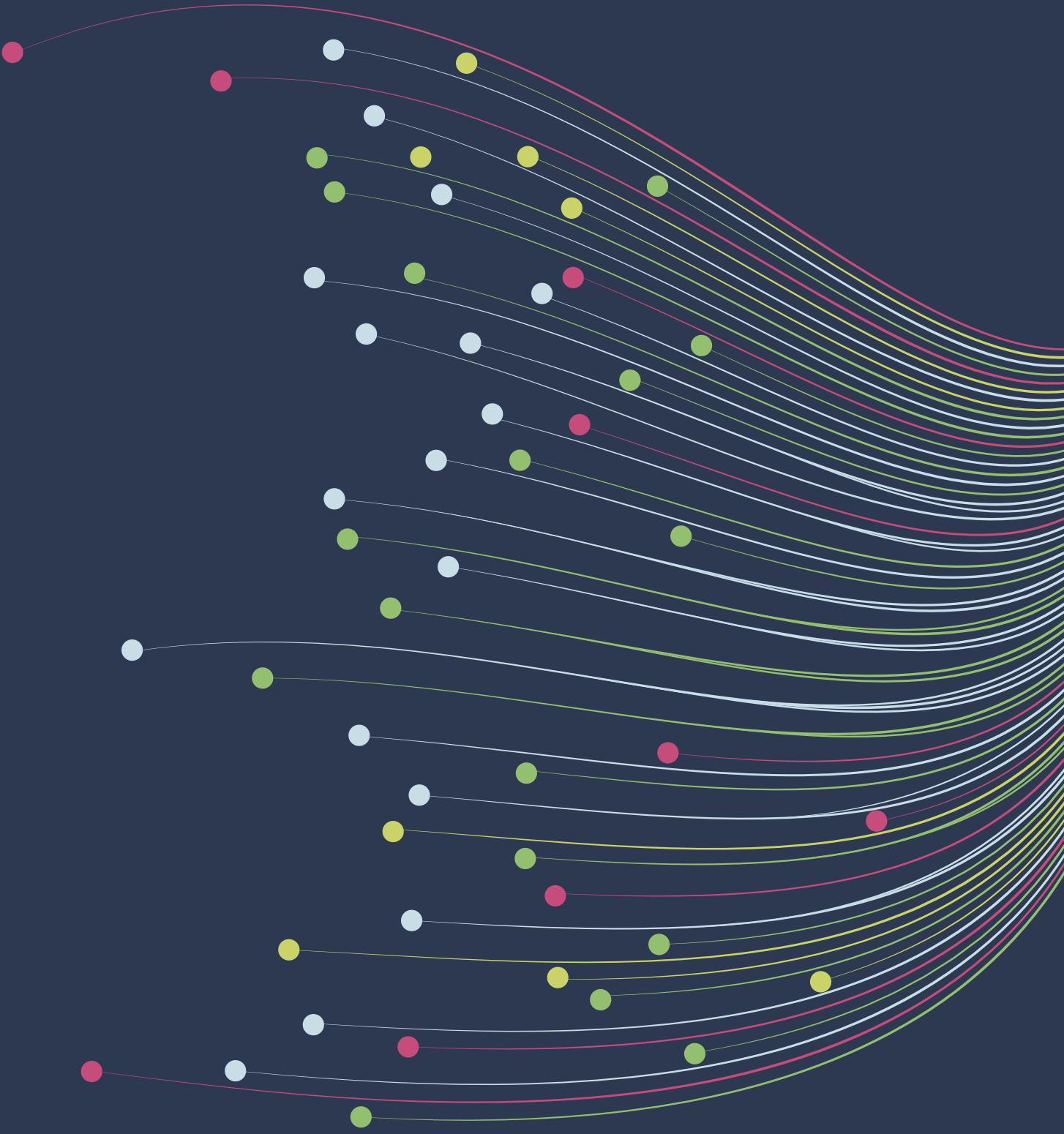
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- Epilepsy Connections: **info@epilepsyconnections.org.uk**
- Epilepsy Scotland: **contact@epilepsyscotland.org.uk**

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