



SPRING NEWSLETTER 2025

Dear Carer & Service User

Time to Live Fund- Our 2024-2025 allocation is now finished. However, this fund will be open again for applications as soon as we receive our next lot of funding, which will be sometime in April or at the latest in May. This funding is specifically for Carers to ensure they can get a break from their caring role and if we can support you with this please don't hesitate to get in touch and we will send you an application form.

Carers Support Group- This group currently meets in the office on the second Wednesday of each month from 12-2pm. Feel free to drop in as you wish and take the person you care for along as well.

Carers Week 9-15 June 2025

This year's campaign will focus on 'Caring About Equality', highlighting the disparities and disadvantages faced by unpaid carers across the UK and calling for a fairer society where they have access to greater support.

There are 5.8 million people in the UK caring for a family member, friend or neighbour who is ill, older or disabled. Unpaid carers save the UK economy an estimated £184 billion each year – the equivalent of a second NHS – yet many feel undervalued and unsupported.

Caring for someone can have a significant impact on your own health, finances, employment and education opportunities. 70% of carers report a long term physical or mental health condition, disability or illness, compared to 50% of non-carers.

We will let you know nearer the time the plans we have in place to highlight Carers Week this year.

Visit to Orkney from NHS Clinical Trials Teams- Tuesday 17 June 2025

The NHS Neuroprogressive & Dementia Network which specialises in clinical trials for Dementia, Parkinsons, Huntingtons, MND and MS are visiting Orkney in June this year. Dr Tom Russ (expert in dementia and author of the book 'FAQ's on Dementia'), Dr Emma Law (Strategic Manager) and Jacqui Kerr (Network manager) would like to hold a session with Carers over lunchtime on Tuesday 17th June at Crossroads. This will be an informal event with Coffee and cake. Time to be confirmed. They will talk about how people can get involved in Clinical Trials in Orkney and what trials are available. More details to follow nearer the time.

ARC Scotland

We have been contacted by Tracey Francis, Policy and Development Worker for ARC Scotland. ARC Scotland is a charity that advances knowledge, practice and policy in health and social care for the benefit of people with learning disabilities or other support needs such as autism, mental health problems, sensory and physical disabilities.

Tracy explains "*Parents and carers of young people with additional support needs say the transition to adulthood is often the most stressful time of all for everyone involved. Compass is designed to help. As the parent of an Autistic adult as well as a transitions specialist, I know having information you can trust is gold dust.*

Compass is a completely free digital tool that gives young people and everyone around them accurate, individually tailored information that is specific to Scotland, at the right time for them, from age 14 to 25.

It was developed by ARC Scotland, is backed by the Scottish Government, and currently has more than 3000 users across the country.

You can find out more here: <https://compasslaunch.scot>.

COMPASS

Parenting a young person aged 14-25 with additional support needs?

Baffled by everything out there?

Knowledge is power – let COMPASS guide you.

A free, online tool with tailored info, a timeline specific to your young person and always up-to-date.

Brought to you by the lived-experience experts 

COMPASS

- Accurate
- Free
- Trusted
- Tailored to you
- Saves you time
- Up-to-date

Young people and professionals have their own versions of COMPASS

COMPASS for young people

COMPASS for professionals

compass.arcscotland.org.uk

Scottish Charity No. SC040294
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Registered Charity No. 285775

Brought to you by the lived-experience experts 

Alison Milne, Trainee Clinical Psychologist, The University of Edinburgh

Alison has been in touch and explained the following: -

"I am a trainee clinical psychologist based in Tayside, Scotland. I would be most grateful if you could bring the study to the attention of any carers who meet the criteria.

- *Participants must be adults who support an adult with a learning disability (also known as intellectual disability).*
- *They can be paid or unpaid caregivers*



Do you support an adult with a learning disability?

Please spend 10 minutes completing a survey about their sleep.

This research is being conducted by Alison Milne. If you have questions, you can contact me at the following email address:
s2464236@ed.ac.uk

You may be an informal caregiver such as a relative or friend of the person. Or you may be a paid caregiver. You must be over 18 years old and support an adult with a learning disability

We are interested in learning what you think about the sleep quality of the person you support and the effect it might have on them and you. Depending on your answers, we might also invite you to take part in an interview

You can access the survey using this QR code or on the following link: [Sleep Survey](https://edinburgh.eu.qualtrics.com/jfe/form/SV_e3Pa4EPRge3ryZg)
https://edinburgh.eu.qualtrics.com/jfe/form/SV_e3Pa4EPRge3ryZg

This survey is part of a project being completed for Clinical Psychology training by Alison Milne, NHS Tayside and University of Edinburgh. Ethical approval granted by the University of Edinburgh. Project number CAHSS2407/07



I am running a research project into the knowledge and attitudes towards sleep held by caregivers who support adults with a learning disability. The first phase of the research is a survey designed to establish an indication of the extent to which people with learning disability might experience sleep disturbance and what the implications might be. The survey can be completed online and asks questions about the sleep of a person that the caregiver supports and what they think about it. Participant's identity will be kept confidential. Participants will not be asked any identifying details unless they meet criteria for the interview phase. I will not be asking about the identity of the supported person in the survey. It should only take up to 10 minutes to complete and will give the research

team an indication of the level and type of sleep difficulties that people with LD experience.

The survey can be accessed below.

https://edinburgh.eu.qualtrics.com/jfe/form/SV_e3Pa4EPRge3ryZg

There is a possibility that survey participants who meet the eligibility criteria will be invited for interview. If this is the case, a more detailed discussion will take place, and any information will be anonymized before being used in an analysis.

This research project has been given ethical approval by the University of Edinburgh, project Number CAHSS2407/07.

Carer Representatives on the Integration Joint Board (IJB)

Orkney's Integration Joint Board has welcomed two new carer representatives with the appointment of Sarah Kennedy and Willie Neish.

Both have personal experience of looking after loved ones and they are equally keen to support other unpaid carers throughout Orkney by being their voice.

Sarah has cared for both her parents with dementia over a seven-year period. She said: "Only when you have been through caring for a loved one can you really understand what it's like. People need a voice from someone who has experience of caring firsthand.

"Unless you have walked in the shoes of a carer, you can never fully appreciate just how lonely a place it can be. I am not an expert at much, but I am an expert in my own story. Whilst my caring experience is coming to an end now – my Dad passed away last year and my Mum is cared for in Smiddybrae House – there are many living this now and others just starting out on a caring journey and I want to be able to help them.

"I want to hear what people are concerned about in terms of being a carer – everyone may have very different issues but collectively we need to be able to share those concerns with the Integration Joint Board and that's where myself and Willie will come in.

"Hopefully, we can all work together to signpost people to the right place and do the role to the best of our abilities."

Willie is Chair of Crossroads Orkney, a charity which was established in 1994 with the aim of improving the life of carers and those for whom they care by giving information, emotional support and practical help. He also has both personal and professional caring experience through looking after loved ones to his time working in various community social care roles.

"I feel I am well placed to understand many of the challenges that carers have daily, especially when caring for a family member. The pressure that you face as a carer can be debilitating at times.

"Respite from caring is absolutely key – everyone needs that time to recharge their batteries to allow them to be able to continuing caring for loved ones.

"These carer rep roles are important to make the IJB aware of the problems and fears carers are facing and the huge pressures that they are under. It's vital that these carers are supported appropriately so that they themselves do not end up suffering health issues. I want to be able to influence decisions that may impact upon carers and ultimately improve the lives of our carers.

"I think it is also important that we raise awareness in the caring and wider Orkney community around the Integration Joint Board itself – who they are and what they do."

Members of the Integration Joint Board recommended appointing Sarah and Willie as carer representatives on the board for an initial two-year period.

If you would like to Contact Willie you can do so by emailing him at willie.neish@orkney.gov.uk We are awaiting contact details for Sarah and will let you know when we receive this.

Council Tax

Did you know that people who have severe mental impairment may be eligible for a council tax discount. Find out more information here [Orkney Islands Council – Council Tax Introduction and Additional Information](#) or alternatively phone the Council on 01856 873535.

Staffing Update- After much thought the time has come for me to hang up my Crossroads hat. I will be in post until mid-May and will then take on a new role at Relationships Scotland Orkney.

May I take this opportunity to thank you for making my time at Crossroads so enjoyable and I wish you all the very best. Crossroads is a truly amazing and vital service which I have been proud to be part of for almost 6 years, firstly at Deputy Manager/Care Coordinator and for the last 3.5 years as Manager.

Rest assured normal service will continue, and the Registered Manager Vacancy will be advertised very soon.

I hope this finds you all well and I wish you all the best over the coming months.

Take Care & Thanks again.

Kind Regards



Registered Manager

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Registered Charity Number SC022786 Co. No. 16342

