

## KEY MESSAGES



GIVING A VOICE TO SCOTLAND'S COMMUNITY LINK WORKERS

## SCLWN: Knowledge Exchange 4 September 2025

### Introduction

Voluntary Health Scotland and the Scottish Community Link Worker Network hosted their latest SCLWN Knowledge Exchange event on 4 September 2025, featuring presentations from the six organisations that make up The Baby Loss Collaborative and Versus Arthritis.

### The Baby Loss Collaborative

The event started with presentations from each of the six organisations which make up The Baby Loss Collaborative. The presentations highlighted the importance of emotional and practical support for bereaved families and the organisations' efforts to provide compassionate care.

#### 1. Antenatal Results and Choices (ARC-UK)

Karen McIntosh from [Antenatal Results and Choices](#) outlined the charity's role in providing support to parents facing difficult decisions during and after prenatal testing and screening. She emphasised the importance of effective communication and support, highlighting that ARC offers a helpline, online forum, peer support meetings, and resources for parents dealing with the aftermath of pre-natal diagnoses. Karen also stressed the need for collaboration with other baby loss support groups in Scotland to ensure appropriate support for all parents, addressing the isolation and self-doubt many experience after making the decision to terminate a pregnancy.

#### 2. Baby Loss Retreat

Bryan Morrison from [Baby Loss Retreat](#) shared their work providing counselling and retreats for bereaved parents, including plans to build a dedicated retreat centre. The Baby Loss Retreat aims to relieve the emotional and psychological suffering to

parents who have lost a baby at any stage. Parents can get six sessions of Counselling or Trauma Therapy from one of their qualified counsellors. After they have completed the counselling sessions, the parents get two days away at one of their retreats in Dumfries or Glenrothes. Parents also get a comfort bag with personal items to support them through the loss of their baby. Bryan shared photos of the retreats and outlined plans for the organisation to build their own retreat over the coming years.

### 3. Held in our Hearts

Nicola Welsh from [Held in our Hearts](#) outlined their organisation's services which include counselling, peer support, and a hospital-to-home support programme. Hospital to Home (H2H) provides support to families whose baby has died after 12 weeks of pregnancy and under school age. The project intends to fill a gap in the transfer of bereaved families between hospital and home by providing bespoke and targeted short-term support to bereaved families. This allows the H2H support workers to **reach in** so families do not have to **reach out** for support. The support includes 6 to 8 visits at home and support with planning funeral and memorial arrangements. Nicola finished her presentation by playing a video of a mother talking about the support she had received from the organisation.

### 4. The Miscarriage Association

Lucy Graham from [The Miscarriage Association](#) started by highlighting that miscarriage is the most common form of pregnancy and baby loss, affecting around 250,000 people annually in the UK. She explained the organisation's mission to offer support and information to those affected by pregnancy loss, including specific campaigns like "Leave for Every Loss" which aims to improve bereavement leave policies. Lucy also discussed the association's support services, such as a helpline, peer support groups, and educational resources for both individuals and healthcare professionals, emphasising the importance of addressing the mental health impacts of pregnancy loss. Lucy shared Shan's story to highlight the impact of pregnancy loss on mental health, emphasising the importance of providing support and understanding.

### 5. Sands

Joanne Robison from [Sands](#) discussed their helpline services, which offer trauma-informed, person-centred support for pregnancy and baby loss, available in multiple languages and accessible to anyone. They are run by a team of paid staff from across all 4 nations to deliver a UK-wide centralised service. They have a free telephone helpline, and provide support via email, webchat, social media, online community message boards and online meetings. CLWs can make referrals to them at [helpline@sands.org.uk](mailto:helpline@sands.org.uk).

### 6. Simba

Sarah Pryde-Smith presented an overview of [Simba](#), a Scottish-based charity that provides support to bereaved families through memory boxes, bereavement rooms, and training for healthcare professionals. She explained that the charity evolved

from a midwife's personal experience of creating memory boxes for families who had lost babies. Sarah highlighted Simba's mission to honour and remember babies, while noting that they do not provide peer support or counselling, as other charities already fulfil this role. Sarah also mentioned Simba's collaboration with other charities and organisations to ensure that bereaved families receive the support they need.

## Versus Arthritis

Jake Sanders from [Versus Arthritis](#) presented an overview of the different types of arthritis as well as management strategies for the condition, highlighting the need for early intervention and self-management techniques.

Jake presented statistics on arthritis and musculoskeletal conditions in the UK, noting that over 20 million people, or one-third of the population, live with such conditions. He discussed the impact of these conditions on working days lost and shared insights from a video debunking the myth that exercise should be restricted for arthritis patients. Jake also highlighted the benefits of physical activity for reducing pain and improving overall well-being and mentioned that only 59% of surveyed individuals with arthritis were aware of the access to work scheme.

Jake spoke about the Arthritis Foundation self-management resources and professional engagement network. Jake also described the Foundation's partnership offer, which provides training for community groups to deliver their services. There was some discussion about the reasons why there is a higher prevalence of women with musculoskeletal conditions, which Jake attributed to factors like menopause, societal expectations, and genetic predisposition.

Finally, Jake shared some links to other resources available through Versus Arthritis's website including Pre/Post Surgery leaflets which can be accessed here: [Free Information Booklets - Versus Arthritis](#) and their Let's Move with Leon Programme: [Let's Move with Leon | Versus Arthritis](#)

## Further information

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