hope for the community

Association of Mental Health Providers

Certified Social Enterprise · Business for Good

Coventry University

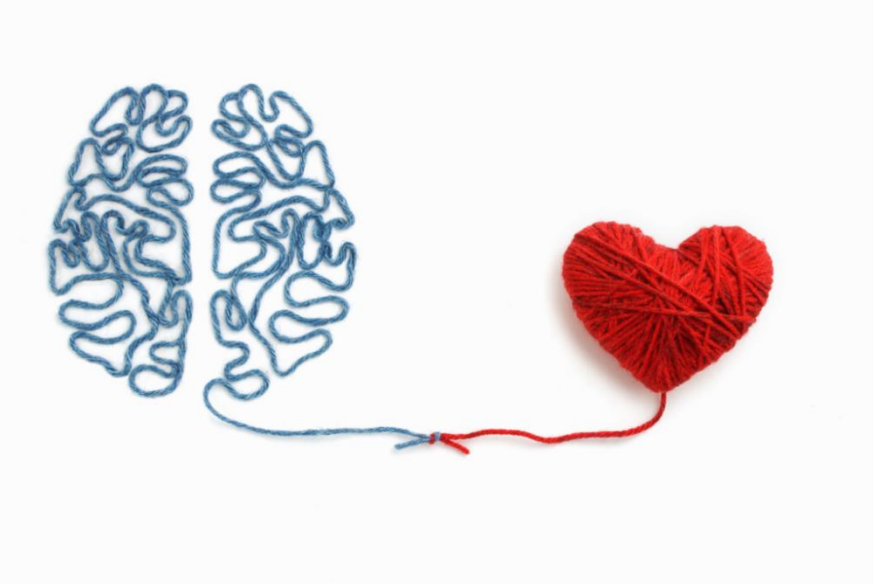
Holistic approach to care for IIH and the Hope Programme

Dr Anna Carlson

9th July 2025

IIHUK Idiopathic Intracranial Hypertension

Introduction and overview



- Setting the context
- Explore a holistic approach to care for IIH
- Overview of the Hope Programme for IIH
- Tasters from the programme for you to try!

From academia to impact and beyond …

- 2015 Community Interest Company
- Research social enterprise spin-out from Coventry University

3 GOOD HEALTH AND WELL-BEING

17 PARTNERSHIPS FOR THE GOALS

- **Empowerment**
- **Self-management of long-term conditions**
- **Digital health**

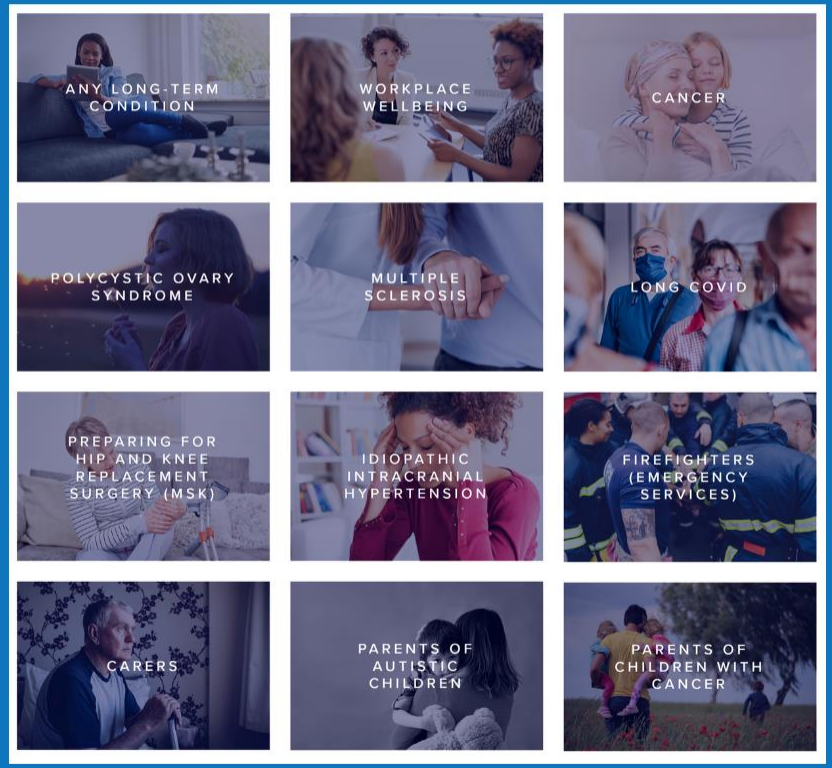
IMPACT & EVIDENCE

the hope programme

28,000

PARTICIPANTS TO DATE

- **85%** PARTICIPANTS REPORT IMPROVED MENTAL WELLBEING
- **30% - 40% IMPROVEMENT** IN DEPRESSION AND ANXIETY
- **40% INCREASE** IN SKILLS TO MANAGE THEIR HEALTH
- **REDUCTION** IN USE OF SERVICES
- **25** PUBLICATIONS WITH RESEARCH PARTNERS



www.h4c.org.uk/research-and-impact

DIGITAL HOPE PROGRAMME
ADOPTION BY TARGET GROUP

the hope programme

Long Covid	3142	24%
Cancer	1909	15%
Firefighters	1610	13%
Parents autism	1205	9%
Carers	1156	9%
Any long-term condition	1075	8%
PCOS	749	6%

IIH	503	4%
MS	392	3%
Parents cancer	284	2%
MSK	190	1%
Unemployed	186	1%
Workplace	172	1%
Parents IIH	127	1%

Customers and funders

NHS England South West
MACMILLAN CANCER SUPPORT
Fire Fighters Charity
IIHUK Idiopathic Intracranial Hypertension
Coventry University
UK Research and Innovation
University Hospitals Coventry & Warwickshire Charity
shaw trust
NHS CHARITIES TOGETHER
CARERS TRUST
verity
thewaterloofoundation
helpcare
Volunteer Cornwall
Aston University BIRMINGHAM UK
West Midlands Combined Authority
heart of england COMMUNITY FOUNDATION
Warwickshire County Council
CU Social Enterprise
SOCIAL CHALLENGES EU INNOVATION PLATFORM
Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER
Bethany's Wish
YORK UNLIMITED MENTALLY FIT YORK
CARERS TRUST Heart of England
Caring Together so that carers have choices
Northamptonshire Carers
ERCC East Renfrewshire Carers Centre
CARERS TRUST SCOTLAND
leeds cares
UNIVERSITY of York
UnLtd
HOFSTRA UNIVERSITY
Enterprise Development Programme
Care for Carers
family voice together improving services
Voluntary Action Shetland Carers
LionHeart Supporting RICS professionals and their families
University Hospitals Coventry and Warwickshire NHS Trust
Wiltshire Health and Care
Magic Square Systems
Coventry University | Online
Atrium Health
Dr Liz Sparkes

A holistic approach to care for IIH

"I feel I am hanging on by a thread – practically & emotionally."

"I feel useless that I'm not the person I was before this."

"I feel like I'm failing as a wife, mum, friend."

"I feel completely overwhelmed."

"I feel isolated and feel friends don't fully understand this."

"I'm so fed up with IIH… I'm in severe pain daily, on the legal maximum of all pain relief and at my wits end."

"I would like my confidence back. Also to be able to hold a normal conversation."

"I want to stop putting my life on hold and start enjoying time with my family."

"It can be lonely and frustrating as I don't feel understood by people around me."

A holistic approach to care for IIH

- 🧩 Need for Knowledge and Understanding
- 🤝 Isolation and Lack of Support
- 💭 Emotional and Mental Health Impact
- 🛠️ Desire for Practical Management Strategies
- 🌪️ Impact on Life and Relationships
- 🌱 Seeking Validation and Shared Experience

Self compassion – the power of kindness

Self-compassion is simply giving the same kindness to ourselves that we would give to others.

— Christopher Germer, clinical psychologist at Harvard Medical School

Self Compassion.mp4

Strategies – Self Care Checklist

What is one thing that you do every day for yourself?

How many activities do you do regularly?

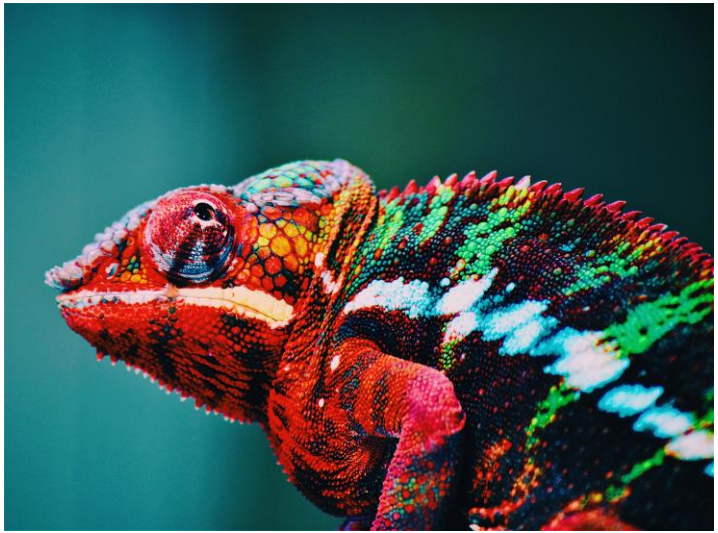
Tünde's Hope Story

Tünde was diagnosed with Idiopathic intracranial hypertension (IIH) around a year before starting the Hope Programme. She had just been trying to deal with all her symptoms and appointments.

Tünde heard about the course from support group IIH UK *"I wanted to find out what I can do to cope better"* she says. *"How should I do things differently?"*

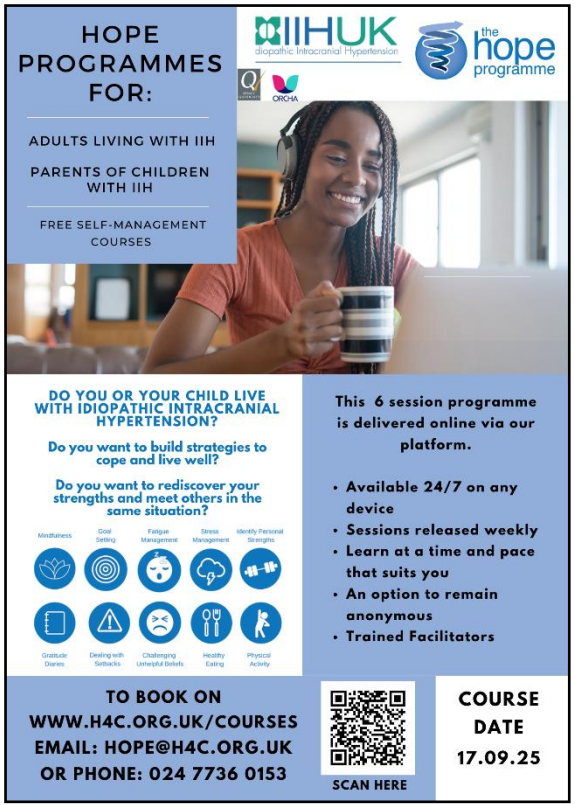
So what did Tünde learn? "*For me it was really beneficial. How to cope with stress and what to do when I'm feeling over-loaded."* But the chance to interact with other people who live with IIH was very helpful, too, she explains.

"*It was good to see how other people were coping. Learning from people who were doing better than me – and realising that I was doing better than others!"* She continues *"It's just really good to be in touch with other people with IIH. To know that you're not alone."*



"With IIH, we change colour according our needs and environment to hide our real difficulties."

Hope Programme for IIH - 2021-2025



668

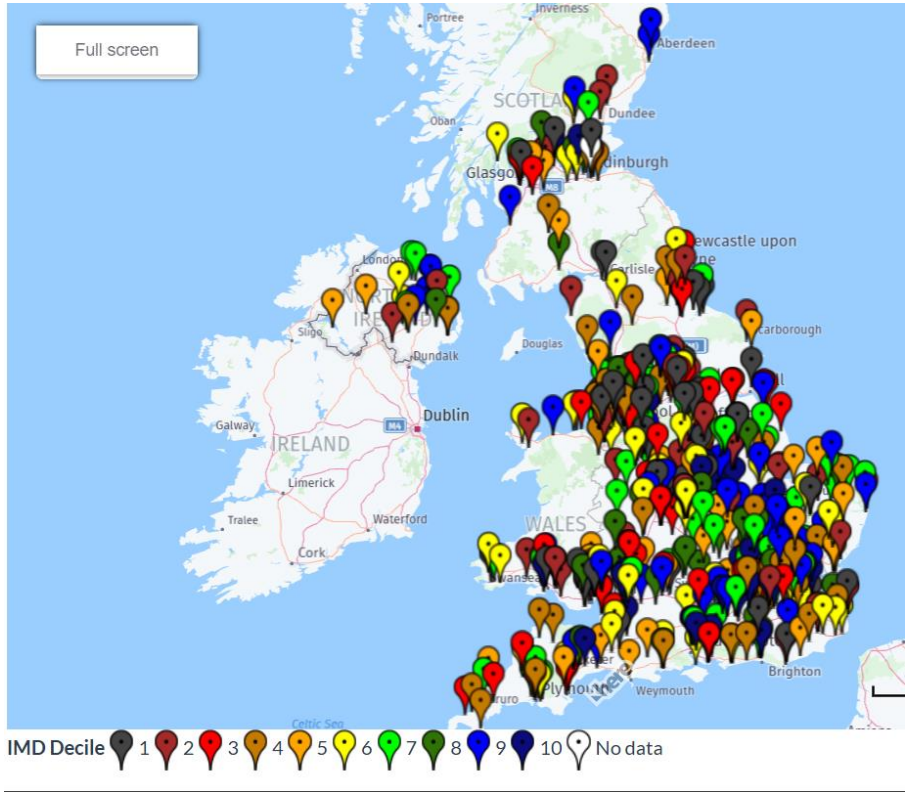
PARTICIPANTS ENROLLED

81 - Parents

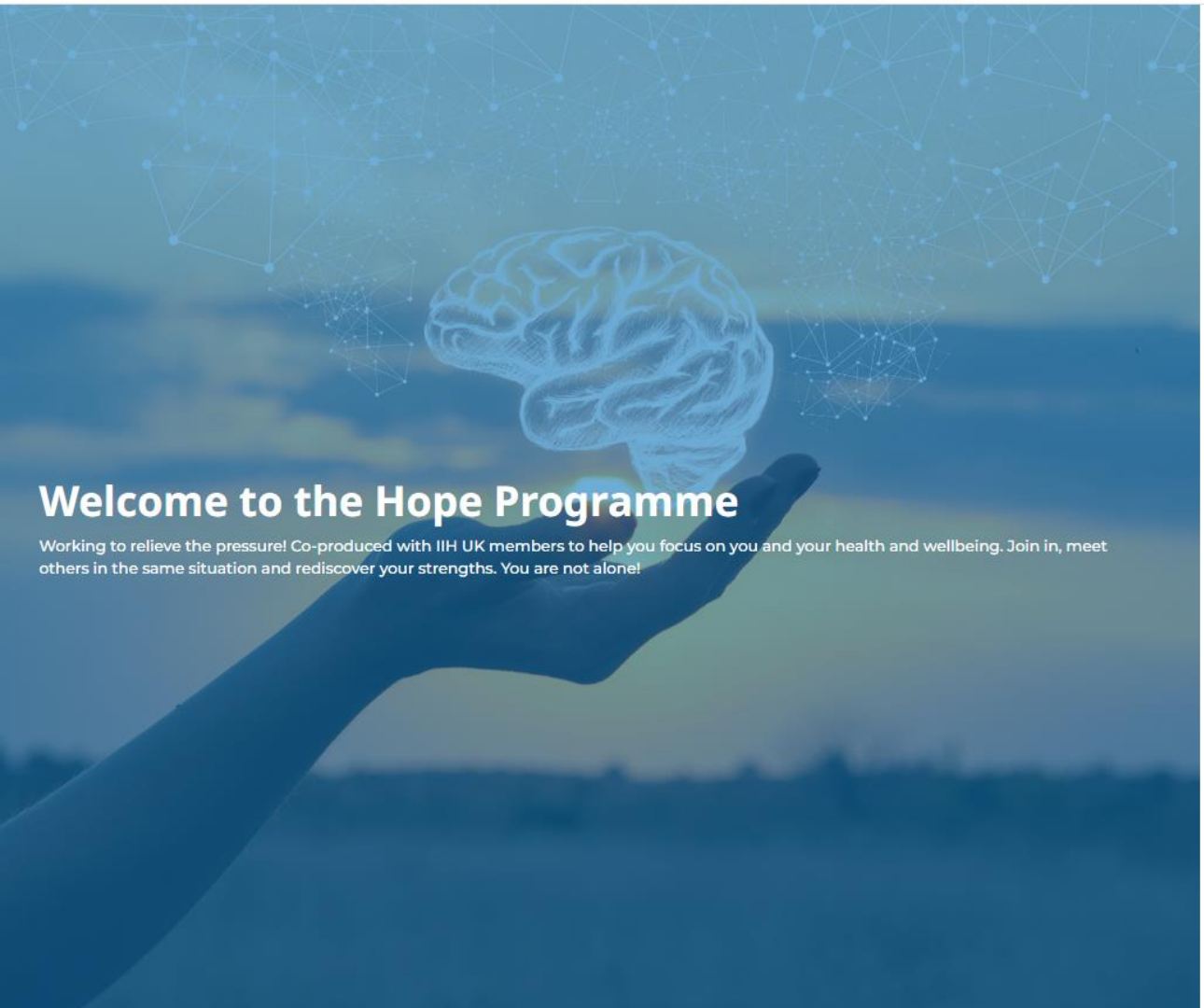
587 - PLwIIH

Ave. age: 38 yrs

Female: 96%



A positive approach to self-management.



Welcome to the Hope Programme

Working to relieve the pressure! Co-produced with IIH UK members to help you focus on you and your health and wellbeing. Join in, meet others in the same situation and rediscover your strengths. You are not alone!

IIHUK

Sign in

Email

Password

Remember me?

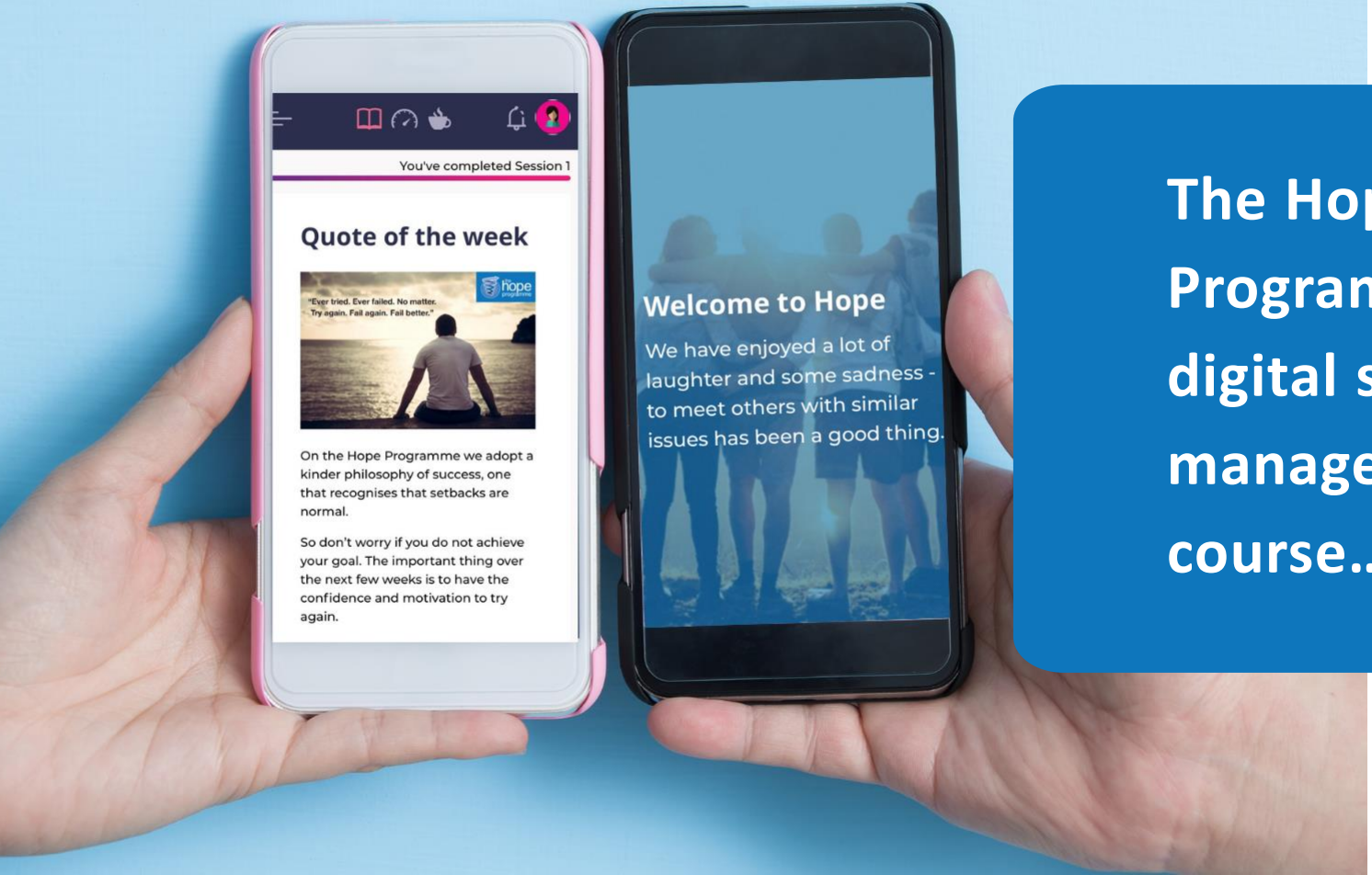
Forgot password?

Sign in

Here is our privacy policy and terms and conditions

Powered by Hope For The Community

WHAT IS...

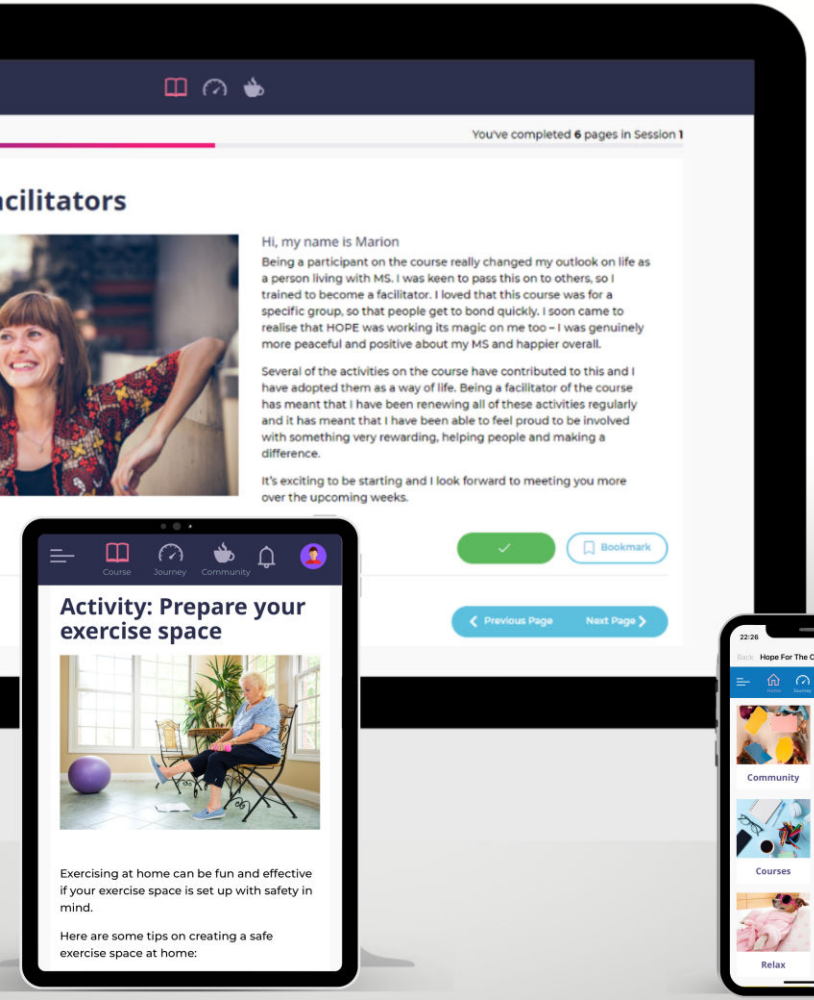


The Hope Programme is a digital self-management course…

Digital

GET IT ON Google Play

Download on the App Store



- All devices & offline
- Asychronous
- Group-facilitated
- Self-directed
- Community

Structured content

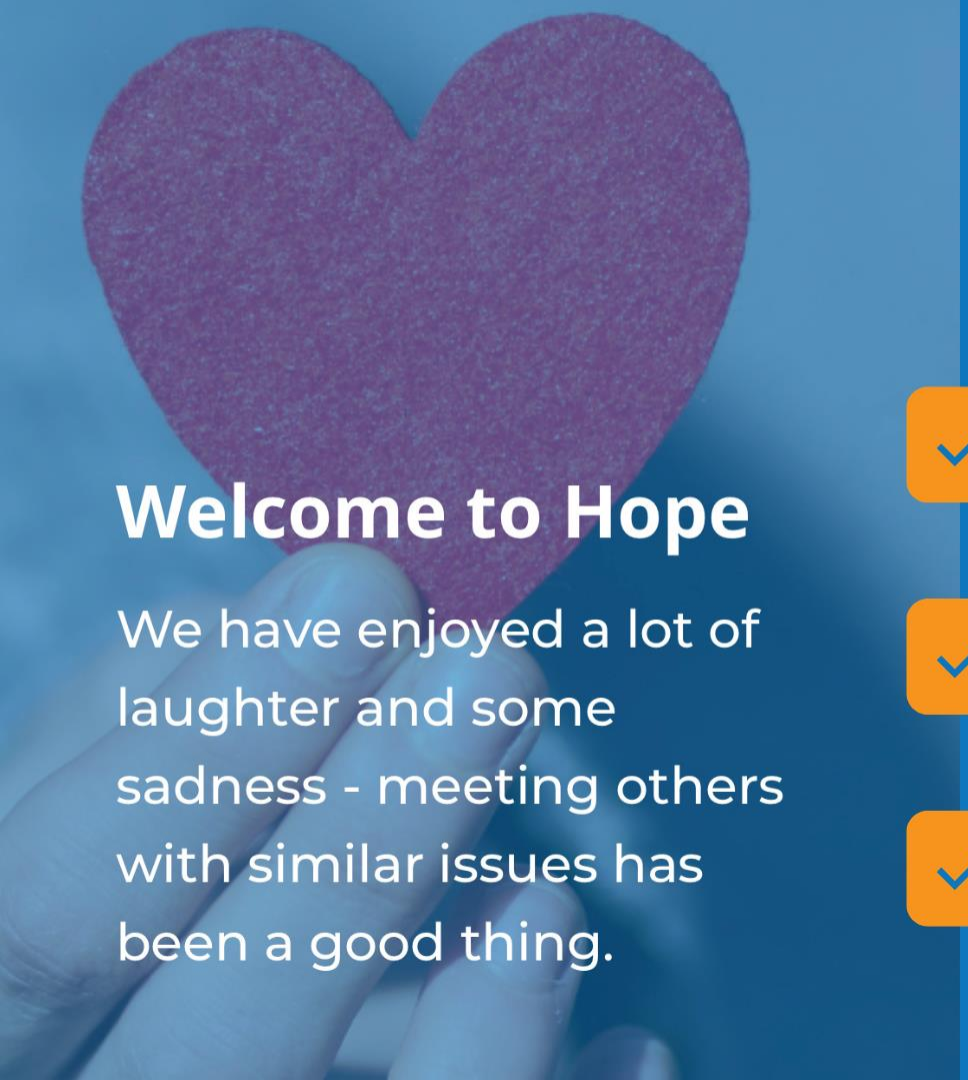
Easy to follow sessions with text and videos

the hope programme

HOPE: HELP OVERCOME PROBLEMS EFFECTIVELY

Behaviour change

Interactive activities, goal setting, quizzes, tests, and trackers.

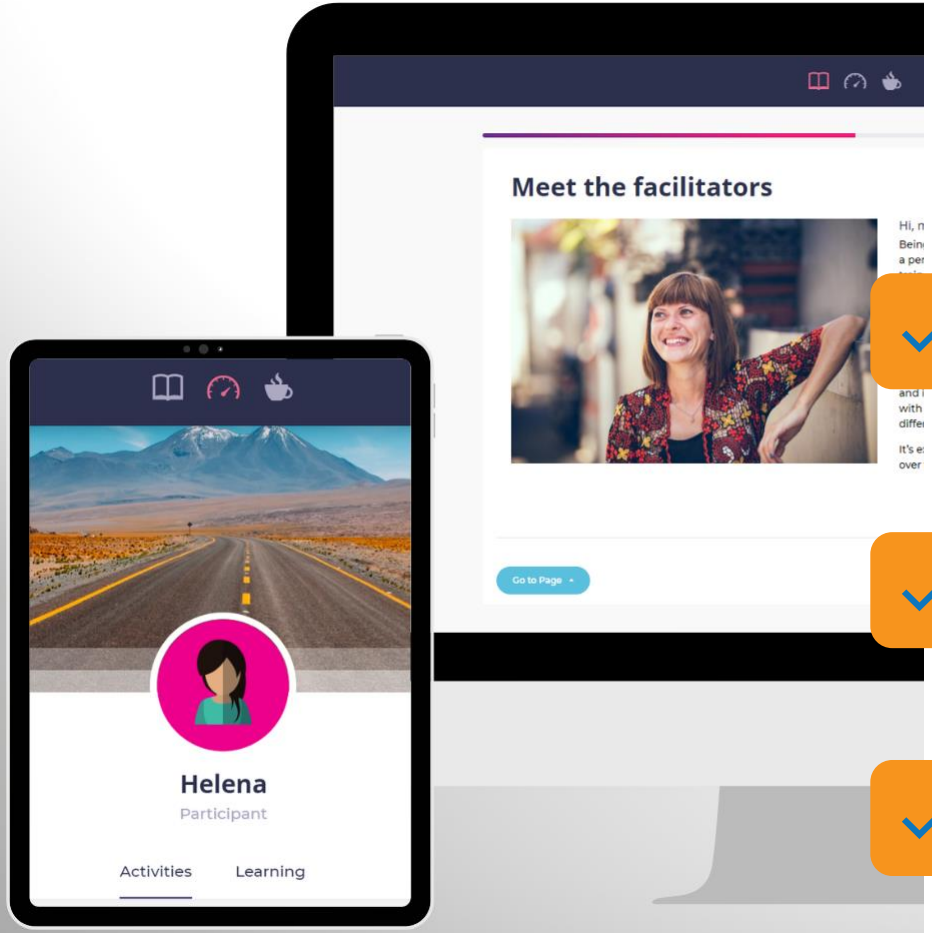


Welcome to Hope

We have enjoyed a lot of laughter and some sadness - meeting others with similar issues has been a good thing.

Flexible

- Groups (80+)
- Facilitated by peers
- Self-directed



Choice and control

- Choice to remain anonymous
- Share only what feels comfortable
- Select ways to be contacted

IMPACT TO DATE

OUTCOMES - MENTAL WELLBEING

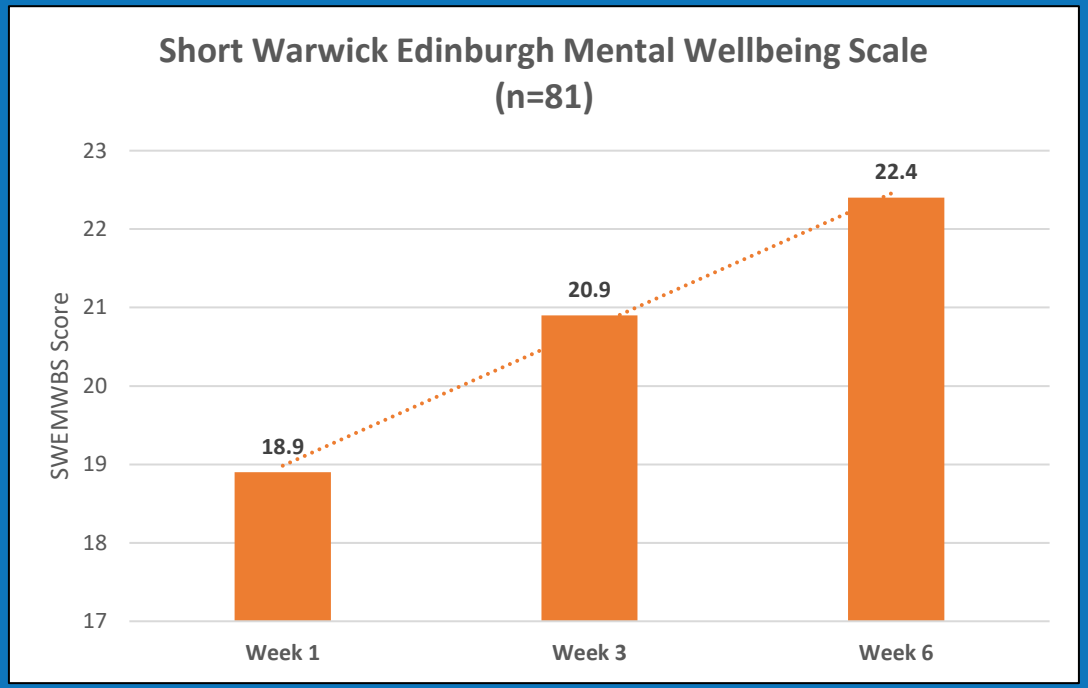
SHORT WARWICK EDINBURGH MENTAL WELLBEING SCALE

A 'meaningful', improvement in SWEMWBS is an improvement of 1 and above.

Participants mean mental wellbeing (SWEMWBS) score was **18.9** before they started the Hope Programme, indicating ***low*** wellbeing and ***probable depression or anxiety***.

Participants mean mental wellbeing (SWEMWBS) score was **22.4** at the end of the Hope Programme, indicating ***average*** wellbeing.

The data shows that participation in the Hope Programme was associated with an **increase of 3.5** (18.9 – 22.4) from pre- to post-course.



Gratitude

What are you grateful for?

I loved this part of the course. I got a lot from having to appreciate what was happening in my life, however small it may have seemed. I also enjoyed commenting on others' posts. It gave me pleasure to pass on positive feelings and see that they were well received.

- Sharon, Hope Programme participant

Feedback

"The programme is like a load of little lightbulbs when you go through each session. There has always been something to apply to my life to allow me to benefit. Learning about IIH is so eye opening and it's helped me see this as just another obstacle in my life but one that's manageable whereas I was so overwhelmed before. Perspective is a great thing to learn."

"The course has enable me to really relax about my whole situation and to help others that are struggling in one way or another with their health problems. It's enabled me to not feel afraid about talking to doctors about certain symptoms because I'm aware of where they're coming from. I have a more hopeful outlook about my illness and that has been a lifesaver for my mental health."

"I have often shared the different mindfulness techniques with friends and family as relaxation is hard to find in a stressed out world. I've often shared with my mum just how the course has given me ideas and helped me to come to terms with certain aspects of my IIH. This has helped her knowing that it's been benefitting me. It's also helped my mental health and she's noticed how this course and being in contact with people who have IIH has really helped me view the illness in a different light."

"It's helped me in coping with this illness and the techniques are something we can all use, not just those who suffer with IIH."

the hope programme
“Ever tried. Ever failed. No matter.
Try again. Fail again. Fail better.”

Be kind to yourself!

This card entitles you to show yourself some kindness and compassion.

Treat yourself as you would treat others.

THANK YOU

Dr Anna Carlson

anna@h4c.org.uk

024773 60153

Hope For The Community CIC is an award winning social enterprise empowering people to manage their wellbeing and to flourish in their working and personal lives.

Social Enterprise UK
Certified Member