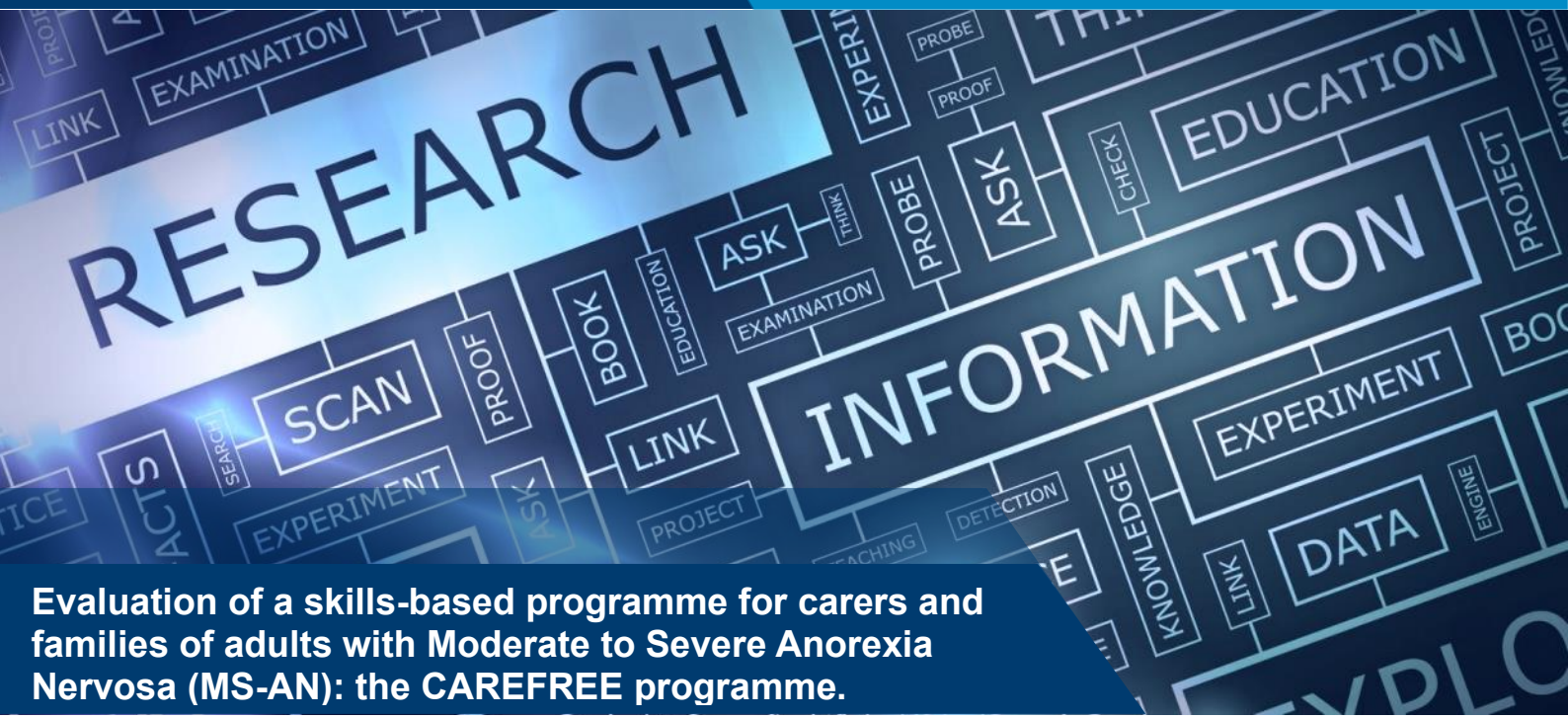
CHIEF SCIENTIST OFFICE

CODE: TCS/22/05

RESEARCH PROJECT BRIEFING



Evaluation of a skills-based programme for carers and families of adults with Moderate to Severe Anorexia Nervosa (MS-AN): the CAREFREE programme.

BACKGROUND

- Adults with MS-AN often have a long illness course, previous non-response to treatment, relapse, and/or complex comorbidity. Family members and partners commonly provide substantial day-to-day support.
- Carers of adults with AN report high psychosocial, financial and emotional strain, affecting quality of life, relationships, communication and their own health and wellbeing.
- Most existing carer interventions have focused on parents of children and adolescents or provide general support. There is limited provision specifically designed for carers of adults with more complex or longstanding AN.
- In Scotland, access to carer support can vary by health board and can be harder for families in rural areas. A national online group was developed to improve access.

AIMS

- To explore the needs of carers of adults with MS-AN.
- To evaluate the feasibility, acceptability and preliminary effectiveness of CAREFREE, a new online Schema Therapy-informed group programme for carers of adults with MS-AN.
- The study used a non-concurrent group case series design: five groups were run over two years, with repeated outcome measures before, during and after the programme. This was a pragmatic first step before a larger trial.

WHAT IS CAREFREE

- CAREFREE is a 12-session online group programme for parents, partners, spouses and other adult family carers of adults with MS-AN.
- The programme is grounded in Schema Therapy, with additional techniques from Compassion Focused Therapy and established models of carer involvement in AN.
- It supports carers to understand AN, carer burnout, emotional needs, coping patterns, family communication and interpersonal cycles that can unintentionally maintain distress.
- Sessions include psychoeducation, practical guidance, group discussion, experiential exercises, imagery and chairwork-based methods, and communication/relational skills practice.
- Participants received session slides and brief video summaries for future reference.

KEY FINDINGS

- 53 carers commenced the programme across five online groups. Participants were adult carers of adults aged over 17 with MS-AN.

- Retention was acceptable: 36 carers attended at least 75% of sessions; 34 completed end-point measures and 33 completed 3-month follow-up measures.
- Carers rated the weekly sessions highly, indicating good acceptability. Qualitative feedback also suggested high satisfaction and reduced distress associated with participation.
- Preliminary findings indicated significant improvements in carer distress, expressed emotion, family functioning, mood and attachment-related avoidance, with improvements generally maintained at 3-month follow-up.
- Some family members with MS-AN also described indirect benefits, although patient outcomes were not the main focus of this initial study. There should be at least 3 or four bullet points

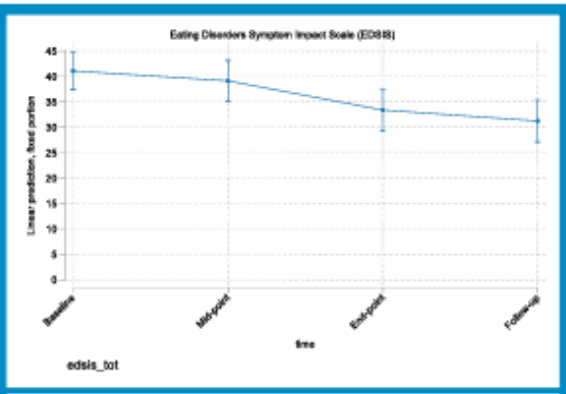
WHAT DID THE STUDY INVOLVE?

- Recruitment: carers were recruited through participating Scottish NHS adult eating disorder services and BEAT Scotland. Potential participants were offered a virtual screening meeting.
- Participants: carers, adult family members, partners or spouses of an adult (>17 years) with MS-AN. MS-AN included treatment non-response, relapse, chronicity over 4 years, complex comorbidity, and/or complex aetiology/pathway.
- Delivery: five non-concurrent groups were delivered online over two years. Each group received 12 weekly sessions of 75 minutes, delivered by two doctoral-level clinical psychologists with specialist training in Schema Therapy, Compassion Focused Therapy and eating disorders.
- Measures: outcomes were collected online at baseline, mid-point (6 weeks), end-point (12 weeks), and 3-month follow-up (24 weeks). Measures assessed carer distress, expressed emotion, family functioning and communication, depression/anxiety/stress, and attachment-related anxiety and avoidance.
- PPI: experts in eating disorders, carers and people with MS-AN were consulted during programme development and review of materials.

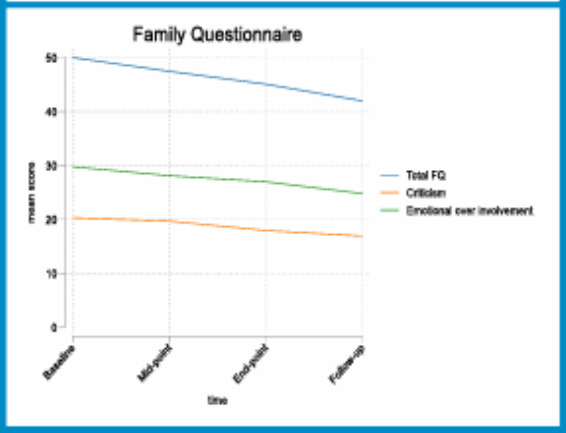
WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

- Carer distress reduced over the programme and remained lower at follow-up. EDSIS total mean score reduced from 41.1 at baseline to 27.9 at follow-up, with reductions in social isolation, guilt, nutritional situations and dysregulated behaviour.
- Family functioning and communication improved. SCORE-15 total mean score reduced from 33.5 at baseline to 28.1 at follow-up; Family Questionnaire scores reduced from 50.0 to 42.0, including reductions in criticism and emotional over-involvement.
- Mood improved. DASS-10 total score reduced from 9.3 at baseline to 6.9 at follow-up, with significant reductions in depression and anxiety.
- The graph time points refer to baseline, mid-point (6 weeks), end-point (12 weeks) and follow-up (24 weeks/3 months).

Eating Disorder Symptom Impact Scale (EDSIS): There were statistically significant reductions in carer distress, guilt and social isolation between pre to post- (and pre to 3 month follow-up).



Family Functioning significantly improved between baseline and 3 month follow-up, with reductions in both emotional overinvolvement and criticism.



* Baseline, mid-point, end-point and follow-up refer to 0, 6, 12 and 24 weeks

WHAT IMPACT COULD THE FINDINGS HAVE?

- For carers: CAREFREE may reduce distress, isolation, guilt and burnout, and improve carers' confidence and communication.
- For people with MS-AN: improved family communication and reduced criticism/over-involvement may create a calmer and more recovery-supportive home environment. Patient outcomes require direct evaluation in a future trial.
- For NHS services: an online national model could reduce inequity in access across Scottish health boards, including for rural families.
- For policy and practice: the findings support further testing of CAREFREE in a larger controlled trial and suggest potential for sustainable, cost-effective roll-out if effectiveness is confirmed.

HOW WILL THE OUTCOMES BE DISSEMINATED?

- One paper has been recently published: Mawdsley, E., McNicol, S., Rutherford, A.C. et al. A case series evaluation of a schema therapy-coaching programme for carers of patients with moderate to severe anorexia nervosa: the CAREFREE programme. J Eat Disord (2026): https://doi.org/10.1186/s40337-026-01704-9
- An additional qualitative paper has been submitted to a peer-reviewed journal; findings will also be presented at relevant eating disorder and clinical psychology conferences.
- Clinical/public dissemination: findings will be shared through NHS eating disorder networks/services, eating disorder charities, and plain-English online summaries for carers and clinicians.
- Next step: a larger trial is needed to test the reliability of the findings and assess whether improvements for carers also translate into measurable benefits for patients with MS-AN.

CONCLUSION

- CAREFREE is a feasible and acceptable 12-session online programme for carers of adults with MS-AN.
- Preliminary evidence suggests improvements in carer distress, mood, family functioning and communication, with benefits maintained at 3-month follow-up.
- A larger trial is now needed to establish effectiveness and inform potential wider delivery across Scotland

RESEARCH TEAM & CONTACT

Susan Simpson,

Emma Mawdsley,

Lesley Symon,

Alasdair Rutherford,

Debbie Smith,

Hazel Elliott,

Ruth Lamont

NHS Forth Valley, with NHS Greater Glasgow & Clyde, NHS Lothian and University of Stirling

simpsosg@gmail.com

CSO awarded £240,415. Project was completed on 31/07/2025.