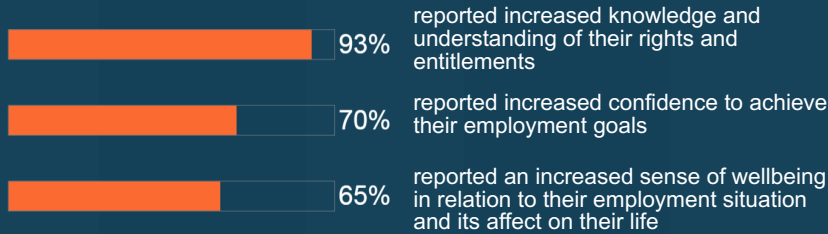


# What difference has SEE M.E. made?

Action for M.E. delivered this 18-month employment support project for people with M.E. who are in employment, seeking a new job or considering how to approach work in the future. SEE M.E. was delivered in partnership with North Bristol NHS Trust, embedding an employment advisor within its specialist M.E. service.

More than 120 people with M.E. were referred or self-referred to the SEE M.E. service. Of those whose relationship with the service came to an end within the timescale of the project, and who responded to independent evaluator follow-up:



"SEE M.E. supported me with my confidence being back at work with my condition, knowing that I'm not alone, knowing my rights and pacing myself." (Client with M.E.)



"Had I not met with SEE M.E. I do not think I would still be in employment. At the time of meeting my employer was in the process of retiring me on ill health grounds. I did not know that they were looking at problems, rather than ways to get me back to work." (Client with M.E.)

"A return to work plan has been put into place with the help of Action for M.E., which has been very helpful in that we have not lost a valuable member of staff." (Employer)

60% of clinicians said SEE M.E. freed up clinical time previously spent supporting patients with their employment needs

This time saving of two hours per week equates to £24,000 per annum



"The project has helped keep me up to date with employment issues and provided support with complex issues so that my clinical time has been used as well as possible." (Clinician)

83% employers or union representatives said SEE M.E. made a positive difference to their anticipated case outcome.

\* Whose relationship with the service came to an end within the timescale of the project, and who told SEE M.E. about their outcome.

## Executive Summary

M.E. is a chronic, fluctuating, neurological illness directly affecting 250,000 people in the UK. Over 90% of people affected report that they are unable to work, study or train full or part-time<sup>1</sup>. For many, this is because they are too ill. For a significant number of others, including those less severely affected and those who have made some recovery, their **exclusion from employment and training arises from a lack of support to build confidence, seek appropriate employment, agree reasonable adjustments and overcome perceived and actual barriers in the workplace.**

Support, Empower and Employ people with M.E. (SEE M.E.) is Action for M.E.'s innovative pilot project to provide that missing support. It is **creating significant value** for people with M.E., for professionals working with them and employers as well as for the wider community.

SEE M.E. offers unique specialist employment advice and support, integrated within specialist NHS clinic provision. The project supports people with M.E. to stay in work (job retention), to access employment (job-seeking), to plan or access other vocational opportunities, or to leave work well where their health prevents them from working. The project was developed in direct response to need identified by clinicians and people with M.E. The service provides a service to people living in Bristol, North Somerset, Gloucestershire and South Gloucester who have a diagnosis of M.E./CFS.

The pilot project concludes on 7 October 2016. At the time of writing, the service has provided a service to 102 people. At an individual level, the service has delivered **improved outcomes for people with M.E.** Of those people who provided evaluation feedback at the end of the support package:

- 72% reported successful job retention or securing appropriate work, training or volunteering
- 65% reported an improved sense of wellbeing as a result of the employment support provided
- 83% had increased access to mainstream services to secure support to meet their need
- 93% reported improved understanding of their employment rights and entitlements.

SEE M.E. has also provided **capacity building** support at an organisational level. 83% of employers/trade union representatives reported that project intervention had made a positive difference to the anticipated employee case, including successful return to work from sickness absence and more sustainable working through increased awareness of M.E. and workplace adjustments. NHS clinicians reported **improved health outcomes** for patients and **improved knowledge and confidence** of employment related matters, enabling better support for patients.

In addition, the project has delivered **cost savings**. Two employers were prepared to estimate cost savings with an average saving of £3,350. The service has delivered 13 successful return to work outcomes to date, and increased the sustainability of a further five, resulting in considerable cost savings to employers (evidence from the National Outcomes Database indicates an average loss of productivity cost due to discontinuation of employment of £22,684 per person per annum<sup>3</sup>). Furthermore, clinicians reported an average of two hours per week of time saved due to service input which generates approximately £24,000 of savings in time per annum. The **social return on investment** calculated using the HACT tool<sup>2</sup> is £5 - £6 for every pound spent.

The project evaluation has identified that:

- Integrated, person-centred specialist interventions deliver **enhanced employment outcomes** for people with M.E.

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<sup>1</sup> Action for M.E. 2014. Time to Deliver <https://www.actionforme.org.uk/uploads/pdfs/me-time-to-deliver-survey-report.pdf>

<sup>2</sup> <http://www.hact.org.uk/value-calculator>

<sup>3</sup> Collin et al 2011 <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-11-217>

- SEE M.E has **met needs that current mainstream employment and health services are unable to.**
- Embedded employment advisers provide **an effective bridge between different agencies in the patient's journey to health and employment**, playing a role which clinical staff have neither the time nor expertise to deliver.
- **Employers, trade union representatives, work coaches and employment advisers (Jobcentre Plus and others) need help** to better understand the employment impact of M.E. and how best to improve outcomes for people affected by it.
- Getting the right support is **effective in preventing a spiral of decline**, both in terms of a person's employment status and their health and wellbeing.
- The project's innovative approach is likely to be **transferable to a range of other fluctuating long-term health conditions.**

Application of the project findings could be used by the UK Government, employment advisers, NHS clinical services and others to **reduce the disability employment gap** by influencing:

- design of the new **Health and Work** programme.
- improvements to **Access to Work**.
- delivery of **support for employers** to become confident and competent to recruit and retain disabled people.
- delivery of **enhanced employment support** by specialist M.E./CFS clinical services.

## CASE STUDY

Fran was referred to SEE M.E. by her specialist M.E./CFS clinician following a relapse which kept her off work for a year. Her employer asked for a return to work date and due to the fluctuating nature of her condition Fran found it difficult to commit to one.

*"The whole idea of trying to go back to work was terrifying because I just couldn't concentrate. I was terrified that I would go backwards and have my contract terminated on the grounds of ill health."*

SEE M.E. met with Fran and her clinician to understand her symptoms, work related challenges and needs and to consider how returning to work might best be approached. SEE M.E. then met with Fran and her employer to discuss what a realistic and achievable return to work plan might look like.

Fran reflects: *"I felt that I had to give it a go. SEE M.E. helped me push for an extended phased return to work. They were very good at hammering out details of what reasonable adjustments I needed. I felt that they came over really well in understanding both the employer and employee situation."*

SEE M.E. helped Fran to set new goals that were about 'returning to work in a sustainable way' and to negotiate an eighteen week staged return to work, extended far beyond the usual six weeks phased return period. SEE M.E. also assisted Fran with her Access to Work application and workplace assessment which led to some very practical measures being put in place.

SEE M.E. Adviser: *"The employer was open to listening to clinical advice and our recommendations for targeting adjustments and support at Fran's specific M.E. symptoms and related challenges. We agreed it would require a more patient approach to building up her hours, which would be carefully monitored throughout. Fran and her line manager hugely appreciated SEE M.E. attending regular reviews to evaluate the effectiveness of the plan and advise where it needed to be tweaked. Including advising they might expect to experience set-backs and to learn from these but not just give up."*

Fran: *"I have started back. It is hard work and I'm coping. It has made the difference having SEE M.E. in direct contact with my clinical support. Having the trust in my clinician and SEE M.E. enabled me to give it a go when I had been really unsure that I could do it. Having SEE M.E. with me to negotiate adjustments and the phased return is what has worked and what made the difference."*