

An unexpected journey: Learning from the experts

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Background

Recognising the growing demand on healthcare, the Scottish Government is seeking to transform service provision. This includes shifting the balance of care, promoting timely, person centred service delivery and encouraging the development of effective self-management as close to home as possible (1,2).

Fatigue is a common symptom for people living with progressive neurological disorders, significantly impacting on function and quality of life (3, 4). Referrals to our specialist Neuro Rehabilitation Outpatient Services (NROPS) are received from a variety of sources with service users often having to navigate a complex system before receiving targeted intervention with this issue. Typically the multidisciplinary team (MDT) have provided a 4 week educational group programme focussing on increasing knowledge, confidence building, self awareness, and developing strategies to manage fatigue in daily life.

The NROPS team recognised a need to evaluate the groups to ensure they best met the needs of the service users and were awarded a small grant in order to undertake this project. Results revealed some interesting findings which challenged our thinking, leading us to reflect on what person centred care really is and how the involvement of service users can enhance programme design as experts in their own conditions.

Embarking on our journey:

Following consultation with service users and review of a pilot group, five education groups were carried out over a 12 month period delivering a variety of educational strategies to enhance self management. A range of outcome measures, including qualitative reports, were applied to elicit how we might further enhance the quality of our service. Carers were given the opportunity to attend one session.

What we discovered along the way:

At the end of the 12 month evaluation period results indicated:

- Group content was relevant, valuable and addressed service users' key issues
- Peer support was recognised as a great benefit, with service users valuing listening and learning from each other
- Carers' knowledge and confidence in supporting loved ones increased
- Service users consistently reported that earlier intervention to discuss fatigue and provide timely advice about its management would have been a huge benefit
- Some service users felt a 1:1 approach may have been more valuable in addressing their specific needs
- Quantitative data, gathered using a variety of measures including The Modified Fatigue Impact Scale (5) showed no significant improvement in fatigue profiles.

Stop, look and listen

The results obtained led us to reflect and consider the value of the extensive learning from our service users. We asked then asked ourselves these probing questions:

- How might we embrace co production in developing interventions going forward, rather than merely consulting?
- How can people receive support & information about fatigue management at the earliest opportunity?
- How can more sustainable peer support be developed?
- How could we work with other service providers to increase capacity and quality?
- How can we best support carers?
- Are fatigue profiles the best way to measure outcomes?
- How can we develop a more personalised approach to fatigue management?
- Is a group the most useful method of building skills?
- What is the specialist contribution in fatigue management?



Taking a different route

As a result of this learning, the need to transform our service was evident. Our priorities included:

- **Developing** resources for primary care clinicians to improve early intervention for those with fatigue based on "5 key questions and top tips" model
- **Improving** triage to ensure service users access the right service at the right time
- **Shifting** from a universal group to more personalised approach to include 1:1 sessions, telephone consultation and support, or a small bespoke facilitated group session
- **Establishing** links with community resources including third sector organisations to explore options for more sustainable peer and carer support.

Until our next journey

This project demonstrates the value of regular service evaluation and engagement with service users to gain their unique perspectives. It revealed the need for timely early intervention, with a personalised approach to manage fatigue thus challenging our conventional practice.

Reflective learning required us to relinquish our role as "experts". We recognised that working in partnership with people living with fatigue, who are the true experts, can offer exciting opportunities to achieve more and deliver better outcomes.



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