

Development of the MS WorkBook:

A toolkit for health and social care professionals to support people with MS in employment

The Project

Methods

Email groups

- People with MS
- Health professionals and Jobcentre Plus Employees

Expert Evaluation

Pilot in Practice

Email groups

- Refining content and structure
- Developing new tools
- Sharing experiences

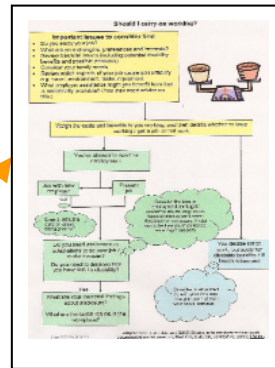
Expert Evaluation

- Vocational Rehabilitation Experts
- Expert Patient representative for Self management aspects

Piloting in Practice

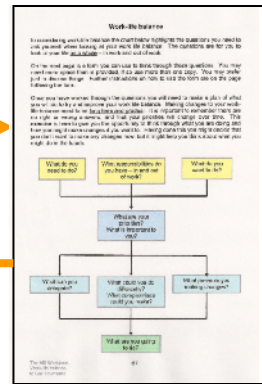
- MS Nurses and OTs
- Up to 2 people with MS per health professional
- Still ongoing

Gail Townsend, Neuro-Vocational Rehabilitation Specialist
Buckinghamshire PCT / Oxford Brookes University



This evolved from an algorithm devised by Kurt Johnson. People with MS added issues they thought needed to be considered.

This tool arose out of the discussion in the email group of people with MS. They thought this was an important topic that should be considered and one that was often neglected by themselves and others



The Toolkit

The toolkit uses the principles of self management to underpin its structure. Self management aims to teach 5 skills

- Problem solving
- Decision making
- Resource utilisation
- Forming patient / healthcare professional partnerships
- Taking action

The toolkit consists of;

- information resources
- Handouts e.g.
 - Disclosure
 - Meeting with your manager
- Worksheets e.g.
 - Travel to work
 - Return to work after sick leave
- Other tools e.g.
 - Work life balance
- Feedback from people with MS in the email group

"Looking at what we have over the past weeks I realise I tend to go along to appointments and focus totally on the medical side of MS that, I feel, is what the professional is wanting to know about – relapses, medication OK/problems, ongoing issues e.g. fatigue and mostly I have left my work persona in the car and mentally tucked work away at the bottom of the pile and never retrieve it while I'm there."

"I really do hope that nurses would also see it as part of their role and want to make use of it as well, I am sure I can't be the only person who only sees a nurse."

"I've found the issues raised very thought provoking and they have given me the impetus to try and "sort things out" for myself. Since taking part in this project, I have been able to have meaningful discussions with my "boss" and physiotherapist and I'm sure my next meeting with my MS Nurse and neurologist will be much more productive"

"Its not just family but the wider need to socialize that keeps people working. Where the family are the carer the individual often needs to see other people for their own sanity and work can often provide this break"

"I suppose one thing I have realised that unless you are the sort of person who is going to be very open and tell everyone (I'm not!) disclosure is an ongoing process as people change jobs and move on and as I discovered last year just because you have done it before doesn't mean it gets any easier."