

# Portal.ms

An Empowering Portal of resources for people with MS.

Short version:

- A crowd sourced portal of information by MSers for MSers
- Allows MSers to make the best use of what is available to them and share opportunities and knowledge with each other.
- Essentially a 'little black book' of links to key information, which can be up voted by peers and potentially verified by Mod's / health professionals
- Information to be categorised under key subject areas for the Shift.ms community - Travelling, going out, at work, family / relationships, Health services, benefits, driving, etc
- would need fairly sophisticated filtering as information might be country specific / city specific / verified or unverified / links from MS Charities etc
- Opportunity to use case studies as a softer way into the resource. Many MSers don't feel they need such a resource, but if we had short video / written case studies of MSers getting on with life, and create listings of all the resources they have taken advantage of to help them get there, should break down barriers to access.

Long version:

## BACKGROUND

Shift.ms is an award winning, independent, user-led social network for people newly-diagnosed with Multiple Sclerosis (MS).

The Shift.ms website was set up in 2009 by George Pepper and Freddie Yauner. George has a background in marketing, while Freddie is a designer. George was diagnosed with MS at the age of 22.

We use creative approaches to communications, and innovative projects, to inspire and empower MSers. The Shift.ms website strives to be a place MSers want to be a part of, and which communicates in ways that MSers relate to and find useful.

Shift.ms works with other MS organisations, including the MS Trust and MS Society, and has recently been awarded the first ever 'Digital Award' at the MS Society Awards in 2013.

**Shift.ms aims to create a positive, enabling community for MSers which empowers them to acknowledge their MS, rethink how to achieve their ambitions and get on with their lives.**

## NEED

As we have seen from the MS Societies recent postcode lottery research; in the UK only a small proportion of MSers are getting access to the services and resources they are entitled to. The report covers issues such as the need for regularity of provision from health professionals, which the portal could make MSers aware of. The opportunity presented to share resources between an empowered community of MSers goes beyond this sort of information into areas of work, family, mobility & transport through to social and lifestyle issues.

There are a minority of MSers who have access to these provisions and are already empowered to take advantage of opportunities - we want to create a portal where this information can be shared with the many.

As seen from the quote below, members of Shift.ms currently have access to peers, who are empowered and this in it self is a positive,

*“other people have gone through this and they have survived and they are living their lives, education, work, children, social lives, holidays, it makes you feel normal again”  
(Tavistock Institute research evaluation, 2013)*

With the addition of a crowd-sourced MS Portal, MSers will not just see empowered others through Shift.ms, but have access to the resources and information they need to become empowered themselves.

We have also seen in research from Berea (*Adjustment to Multiple Sclerosis: application of the Fennell Four Phase Model and identification of effective social support*, 2010) that other MSers are seen as an important source of supportive acts, second only to the support provided by GPs. With this clear need in mind we plan to build a dynamic portal of resource for MSers.

## PROJECT OVERVIEW

Portal.ms will be a crowd sourced portal of information - by MSers, for MSers. Allowing MSers to make the best use of what is available to them and share opportunities and knowledge with each other. Essentially Portal.ms will be a ‘little black book’ of links to key information, which can be up voted by peers and potentially verified by Shift.ms Moderators or Health Professionals where needed.

The information will be categorised under key subject areas for the Shift.ms community - Health services, travelling, going out, at work, family & relationships, benefits, driving, etc. Visitors will be able to navigate the information in both structured and informal ways. We will use tags to filter information to allow browsing in a range of ways including: by topic, location specific, verified or unverified content, best links from MS charities.

To allow for a different more relaxed browsing opportunity, we will introduce case studies of specific MSers and the sets of resources they have used as a softer way into the resource. For instance we will have a case study of 'Toby', who has just been travelling and dealt with health care in different countries, travel insurance and various pieces of ingenious kit to stay cool - while 'Kate' has got grants for home adaptations including preparing her current house for future mobility issues, a car parking space in front of her house and much more.