

# Setting-Up a Support Group for Multiple Sclerosis Patients in Goole, East Yorkshire

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## INTRODUCTION

It was the Goole Hospital physiotherapy department that first came up with the idea for a support group for patients with multiple sclerosis (MS). The group initially had around 30 patients. Unfortunately after review locally, the group was seen not to be cost effective and requested to close.



Although deemed not cost effective, it was clear that this support group was wanted by its members, and finding a way to continue the group and improve on its beginnings was important.

A meeting was held with the specialist nurse, senior physiotherapist, occupational therapist, physiotherapy assistant, and representatives from the MS society local branch. The meeting was primarily to look at where we wanted the service to go. The Getting to Grips course was used as a template for the group. A further meeting was then scheduled to find out the logistics of the group.

## WHY WAS THE GROUP NEEDED?

- The catchment area has the second highest incidence of MS in the UK
- The group was the best use of professional time, with less need for individual consultations
- The nearest group available before now was 30 miles away
- It is important for its members to have social interactions and to have support from their peers
- Carers were also offered support, or could use this time for some respite
- The service is proactive rather than reactive and fits in with Government service delivery

## AIMS OF THE GROUP

- The aim was for the members to manage the group themselves with support from the professionals.
- The group was a mixed group of people with SPMS, RRMS, and PPMS

## WHERE?

- The local community hall was chosen for the group's meeting place, located in the centre of Goole
- The hall had wheelchair access, and two rooms; one for socialising and the other for activities
- The meeting was held for 2.5 hours per session on the first Wednesday of every month
- Given its location, there were three different trusts involved. The MS nurse worked for Hull and East Riding Trust, the physiotherapists were from North Lincolnshire and Goole NHS Trust, and the occupational therapist worked at East Riding of Yorkshire PCT. This made the logistics of setting up meetings and putting the idea into practice challenging

## COST EFFECTIVENESS

- By bringing in a physiotherapist, occupational therapist, and a specialist nurse regularly to the meetings, it enables them to see more patients at one time and in one place
- The local MS branch helped with the costing of the meeting in the first instance
- The members pay a sub of £2
- The members were given the task of printing flyers to advertise the group



## THE FIRST MEETING AGENDA

- Start off with a talk / discussion from the various professionals
- Tea / coffee and social support
- Exercise / relaxation program from the physiotherapy aid and occupational therapist
- Massage / reflexology from the complementary therapist provided by the local MS branch (all through the session)

The meeting is now held at the Courtyard (right)



## EDUCATION

- After the first three months the educational element of the meetings was requested by the members
- Talks included:
  - Overview of MS (MS nurse)
  - Relapse management (MS nurse)
  - Fatigue management (occupational therapist)
  - Dietetics and MS (dietician)
  - Welfare rights (social services)
  - Stiffness and spasm (physiotherapist)


## FOR THE FUTURE

- The group are to carry out their own fund raising to keep the group going
- We have now received sponsorship for the next year
- From the success of this group the local MS branch is looking into setting up another group in East Yorkshire covering another rural area that has limited services

The group!



For further information please contact Mandy Pape: Mandy.Pape@hey.nhs.uk

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