

# What this booklet is about

Over the past few years there has been a considerable number of initiatives to help people with disabilities to gain more control over their lives and to widen the range of facilities and opportunities available to them. These include:

- Moves by the British Medical Association and a number of health service professionals to encourage partnership between patients and professionals and to acknowledge that people with long-term conditions are the ‘experts’ in managing their disability.
- The ‘Expert Patient Programme’ was developed by an alliance of voluntary organisations (the long-term Medical Conditions Alliance, LMCA) and is now promoted by the Department of Health. It aims to provide people with long-term disabilities with the knowledge and skills required for them to take more control over their lives (more details given towards the end of this booklet).
- Initiatives by the Sainsbury Trust and others to involve users in monitoring services and in identifying the wide range of needs, including particularly the more subtle or ‘hidden needs’, of people with a disability.
- The option now available to everyone who is disabled enough to require support or care to receive a Direct Payment so that a person (or persons) can be employed to provide this (more details again given towards the end of this booklet).
- Encouragement by a variety of organisations and professional groups to provide patients and people with disabilities with copies of their own records, and even to be the principle holder of their own ‘person held’ records.

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This booklet has been produced in response to these various initiatives. This is a first draft, and the main aims are (1) *To find out how acceptable the idea is to users* and (2) *To obtain comments and suggestions for improvement.*

We hope eventually to use your suggestions to create a more final version which meets the needs of all users and which users are entirely happy with. Even then it is likely that the booklet will evolve as new developments occur and as the needs of users change with time.

Name:.....

Date of Birth: .....

Address:.....

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Postcode: .....

Other information:

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## **Checklist of activities, opportunities, ideas and people**

*This checklist may help you to complete some of the first few pages of this booklet (pages 3 to 8).*

- Need for social contact, “someone to talk to”.
- Need for someone to help me with hobbies, recreational / leisure pursuits.
- Need for someone to take me out shopping, to places of entertainment, galleries/museums, libraries, the countryside etc.
- Help with gardening or minor household replacements/repairs
- Difficulties with transport/getting around.
- Help with finances and/or legal affairs.
- Introduction to or help with sexual relationships
- Help to control symptoms such as pain, depression, fatigue, stress.
- Need for exercise and things to do
- Holidays and short breaks for yourself; respite for your carer(s).

# **What I would like to be able to do (1)**

**In and around the house/garden**

**In the neighbourhood**

**Further afield**

# **What I would like to be able to do (2)**

**Work**

**Recreation/sports**

**Leisure**

## **What I would like to be able to do (3)**

**Further education/classes (eg art, music, hairdressing, embroidery)**

**Other creative activities**

**People, services and other sources of help which would be of most assistance to me in achieving my aims**

**Other things that are important to me**