



# Taking Care of Myself: A Self Care Management Plan for Patients with Chronic Obstructive Pulmonary Disease

## Keywords:

Self care, self care management plans, chronic obstructive pulmonary disease, collaboration, patient and carer involvement

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## Project leaders:

Myra Savin, Partnership Manager  
Lisa Pendleton, Community Matron

## Contact details:

Myra.Savin@hounslowpct.nhs.uk

## Summary of project

This project aimed to improve the self management skills of patients with COPD by developing and introducing a self care management plan. A collaborative approach was used to develop the plan which involved a wide range of professional and lay participants gathering and considering evidence from a variety of sources, including patient experience.

The self care management plan was piloted by thirteen patients and they reported that they thought that it was well designed and attractive and would be useful in managing their daily lives with COPD. The plan will now be used in a new COPD patient pathway and is available to all GPs, health professionals and patients and carers.

A number of other outcomes were achieved as a result of the project including the creation of a local Breathe Easy group.

## Background

This project was initially stimulated by the project leaders, a Partnership Manager and a Community Matron, whose roles focus on improving patient independence, enhancing choice and the realisation of potential well-being and quality of life.

Self care management has been in the health arena for some time and there have been various attempts to implement it through health professionals and clinical pathways (Department of Health, 2005). It has been central in many government initiatives, white papers and policies (Wanless, 2002; Department of Health 2005, 2006).

Hounslow Primary Care Trust (PCT) had previously developed a self care management strategy, through the self care management strategy group; however, as the organisation had other urgent care pressures, self care management (while seen as an effective toolkit for both patients with long term conditions and staff efficiency) was not adequately developed throughout all services. Although many of the Community Matrons were involved in self care management for patients with long term conditions, the project leaders were aware that there were still many patients who were more likely to present at accident and emergency with exacerbations and have a short stay in hospital before returning home; which could become a repeating pattern of care. The project leaders therefore considered that a well

constructed, patient focused management self care plan would be a further step towards working together with patients, their families and carers to improve well being by encouraging greater confidence in self care management. It would also provide a good example of how self care management can be implemented.

Initially the project leaders were undecided about what condition would benefit most from a self care management plan approach. In discussion with one of the senior managers for urgent care, both chronic pulmonary obstructive disease (COPD) and asthma were raised as possibilities. Further exploration identified that whilst it was expensive to treat both these conditions and there was often an unnecessary loss of quality of life, the form of these respiratory diseases, treatment, care and medication are disparate. The decision was therefore made to develop the project exclusively for older people with COPD.

As the project rationale was based on creating a way of improving independence and choice for patients with COPD, who had been identified from two of the Community Matrons caseloads of being capable of 'taking care of themselves' but who required more support and information to enable them to do so, 'Taking Care of Myself' became the name of the project.

## Aim of the project

The aim of the project was to improve the confidence and self management skills of patients with COPD in a community setting. This would be achieved by:

- Providing guidelines to support patients using a personalised patient action plan
- Educating patients, families and carers in the correct use of medication
- Allowing patients to maintain personal choice and optimise their wellbeing
- Educating health and social care staff in the use of personal self care plans coupled with self management to allow greater independence and understanding
- Organisational support which values, promotes and enables self management to occur thereby enabling patients to continue to live at home and ensuring that patients and healthcare staff are supported and encouraged to make this a successful transition
- Ensuring the continuing support of a Community Matron, working in partnership with GPs and health professionals

## Methods and approaches

The project leaders wanted to use methods to inform the development of self care management plans that involved gathering and using evidence from a variety of sources, including patient experience and which encouraged and enabled the active involvement of all stakeholders, particularly patients. This was achieved by:

- Forming a steering group and a working group that involved health professionals, patients and carers
- Interviewing patients in the community
- Inviting patients to complete diaries

Each of these approaches will be discussed in detail in the following sections.

# FOLIOS

## Steering group

A steering group was formed to provide direction, leadership and accountability for the project. The group had multidisciplinary representation which consisted of an invited group of clinical, management and social care staff, together with patients, carers and members of a local Breathe Easy respiratory group. They acted as critical and questioning advisers to ensure a systematic process of development and to enable the integration of the self care management plans into relevant agendas within the local health and social care community.

The steering group met approximately every three months for the duration of the project and was guided by agreed terms of reference.

## Working group

### Establishing the group

The project leaders wanted health professionals, patients and carers to be actively involved in the project so that views from all perspectives could be used to inform the design and evaluation of the self care management plan. They found that their individual and diverse networking knowledge was exceptionally useful when trying to create a working group (and steering group) that could offer a well balanced perspective. Many people were approached and invited to become a member of the group and the resulting group of twenty two members included a wide range of participants including representatives of commissioning, clinical services, patient groups, carers and the local authority.

The group met for two hours every month over the two year project. Initially the meetings were held at the local hospital but with the opening of a new local health centre, meetings were then more conveniently located there. This change in venue did however have an effect on the ability of the hospital based staff to attend, to a point further on in the project, where there was no representation from the acute sector (including the acute respiratory nurse lead, older peoples discharge nurse and respiratory consultant). The project leaders were however reassured that the respiratory consultant noted the contents of the minutes of the working and steering groups. Patients, carers and other members of public were all offered reimbursements for travel expenses but these were refused which demonstrates the commitment and generosity of the group members.

### Enabling partnership working

Having the involvement of patients, carers and families as identified 'stakeholders' was considered to be paramount. The project leaders recognised that a number of approaches could be used to promote effective partnership working and in particular to ensure that lay participants had the same level of influence and input as the health professionals.

A briefing paper was shared at the first meeting to ensure that all members were clear about the remit of the project and their commitment to the process. Following this, the group developed terms of reference and other necessary guidelines to determine the efficiency and regulatory intent required, for example confidentiality, health and safety, patient experience and public and patient public involvement strategies.

Initially, the project leaders made assumptions that there may be barriers to working collaboratively. It was anticipated that healthcare professionals may not let patients make their own decisions and that some patients and their relatives may think that they were not capable, or not want to make the decision to self manage (because of concerns about making the wrong decision). The project leaders realised that they needed to be open and honest about such assumptions and provide opportunities to identify those of others so that they would not become barriers to the group working effectively. To achieve this, the project leaders facilitated the group using a philosophy of "everyone having something valuable to contribute and everyone appreciating each others opinions and views".

This philosophy was further supported by a group discussion to facilitate the involvement of and understanding between different stakeholder groups. This was informed by Fourth Generation Evaluation (Guba and Lincoln, 1989) whereby stakeholder inputs are defined as claims, concerns and issues and arise from their experiences and perceptions of the service and the values they hold about it. Using this approach enabled the group to recognise that not every stakeholder had the same experience, not every health professional used the same technique, but that there was a common understanding that working together was a privilege for both, because everyone has a 'stake' and something of value to offer. This helped both stakeholders and health professionals in agreeing common purpose.

The experience of the working group was very positive as all the stakeholders were well regarded. Informal feedback from patients and carers suggested that health professionals were felt to be welcoming and accommodating and that group members did not feel any discernable difference between the two. Some stated that it was a privilege to work with the health professionals and a patient recently commented that they missed contributing to the project.

At first, the project leaders were concerned that there may be some issues relating to a conflict of interest as many of the patients in the group were actually patients of some of the staff involved. However, this relationship worked particularly well; there was a fostered confidence and awareness of each others strengths, both having had previous understanding of each others situations. A co-operative approach was adopted by the health professionals – working with people rather than doing to. A particular example of this was when it came to making design decisions on the self care plan. Whilst the graphic designer could offer professional advice on layout and appearance, the group acknowledged that as the plan was ultimately to be used by patients and carers, it was absolutely necessary to have the 'stakeholders' as major decision makers. This required the plan to be written and approved by them too, a role which they willingly undertook.

However, the group also had to acknowledge and work with differences in stakeholder views and perspectives. For example, there was great deliberation over the photograph that would be used on the plan and ultimately, the lay stakeholders selected one that the health professionals would not have used as they did not feel that it was not representative of the community. The lay stakeholders thought that the photograph was perfectly adequate and thought the health professionals had too many concerns.

## Creating the self care management plan

The self care management plan was created by the working group. The process involved reviewing existing plans and other evidence, interviewing patients and collecting patient diaries.

### Reviewing existing self care management plans

The working group identified that the first task should be to identify what already existed in terms of self management plans for COPD. The group collected six plans from patient groups, primary care and acute trusts as a first point. The group reviewed the various plans to identify perceived advantages, disadvantages, other information and suggestions. This led to a detailed analysis and the conclusion that the new self care management plans should:

- Be understandable for patients/carers with clear terminology and directions
- Have contact information for the respiratory team – especially out of hours
- Use a readable size print/font
- Use colour
- Include a traffic light system as alert prompts
- Have less pages
- Use good design
- Use a checklist
- Include medication information/advice

# FOCUS

This information was considered along with national guidelines on the management of COPD (NICE, February 2004).

## **Patient interviews: pre-self care management plans**

To collect patient feedback that could inform the further development of the self care management plan, the working group designed a pre and post patient interview data collection proforma. This included questions relating to the patients' understanding of their illness and medications, how their illness affected their well being and what might help self management of their condition.

A cohort of thirteen COPD patients was selected from the Community Matrons' caseloads. This selection of patients was based on the severity of their COPD, exacerbations, visits to accident and emergency and considered ability to self manage and improve their condition. All the patients who were selected agreed to be interviewed. The selected patients and their carers were contacted by the Community Matron and subsequently visited by the project leaders in the community and in residential nursing homes. Their views were sought on whether a self care management plan would be of value and how and what they saw as important to include in the plan. Both verbal and written consent was gained from all the patient and carers involved. The project leaders used an interview guide and created a written record of the patient's responses. The information collected through this process was shared with the working group to enable all members to develop a greater understanding of what it was like to be a patient with COPD (particularly housebound patients) and then discussed and used this to inform the content of the self care plan.

## **Designing the self care management plan**

Having collated all the desired content and based on the amount of time the group were spending designing the plan, the decision was made to employ a professional graphic designer to ensure that the plan was vibrant, accessible and comprehensive, without being overwhelming. The graphic designer attended some of the working group meetings and explained how the group could best achieve an accessible document. Once a final design was agreed, a few plans were printed for use in the piloting process.

## **Piloting the self care management plans**

All of the thirteen patients who were initially interviewed were invited and agreed to use the self care management plan for a period of six weeks. They were also asked if they would complete a diary for the same period of time. This information would then be used to inform the further development of the plans.

## **Patient interviews: post-self care management plans**

The project leaders arranged to revisit the patients who had been using the self care management plan. It was not possible to interview all of the original patients as some were too unwell and some had unfortunately died, therefore from the original thirteen patients, six were re-interviewed. These interviews enabled the working group to gain patient's perspectives on the value of the self care plan and identify any changes that were needed.

The patients reported that the plan helped with self care management by offering practical suggestions on healthy diet, staying calm and relaxed and keeping warm. They believed that it increased their understanding of how to manage their condition by recognising the stages and taking medication regularly. One patient reported that it had helped her to control her chest infections and reduced the number of hospital admissions. Patients felt that the plan was clearly written and they liked the traffic light system. Some patients did however suggest that the plan did not help with self drainage and specific lung conditions and one patient would have liked more information about other related conditions e.g. bronchitis. Many patients stated that they would

recommend the plan to others because it told them what to do when they felt unwell based on best research and this relieved panic or stress.

## **Patient diaries**

All the patients that were initially interviewed were asked if they would be willing to complete a daily diary for six weeks to provide information about health patterns and lifestyles. Two patients were able to complete the diaries and their experiences suggested that families played an important part in the patients' daily lives as they were dependent on family members for their social and day to day activities. The weather was also a significant influence on day to day activities. The information collected from the diaries informed the plans by ensuring that they recognised family and friends as a valuable source of support for self management and alerted patients to the major effect that the weather can have on COPD.

## **Impact of the self care management plans on patients' daily lives**

Feedback from the patients and carers involved showed that the draft plan had been well received and was found to be very helpful. One of the patients wished to keep a draft copy and said it was like having the Community Matron in her home! Others felt it gave them confidence and understanding of what to do. This was especially true in relation to patients' decision to use rescue packs (steroids and antibiotics), as many patients and carers needed confidence and guidance on when to take the medication; when not to take it (for example, for just colds); and when to get their medication reviewed and dispensed so they were never in a situation where they did not have any or enough.

The use of the traffic light system within the self care management plans was appreciated, as the patients felt that they could anticipate when they were getting worse and this prompted them 'to take care' (a phrase that arose out of discussions in the working group), which could prevent them going into hospital.

Overall, the patient feedback reflected that they thought that the self care management plan was well designed and attractive and would be useful in managing their daily lives with COPD.

The self care plan will be used in a new COPD patient pathway and is available to all GP, health professionals and patients and carers. Following this continued rollout of the self care plans, there will be further monitoring and data collection from patients, health professionals and others who have been involved in this project, to inform future development.

## **Other successful outcomes**

A number of other outcomes were achieved as a result of the project. These will be briefly outlined below.

### **Breathe Easy Group**

The British Lung Foundation (BLF) has been active in creating 'Breathe Easy' groups. These groups existed in neighbouring boroughs and some of the patients involved in this project attended these groups. The Chairs of two neighbouring Breathe Easy groups were part of the working group so with their guidance and the support of the BLF, a 'Hounslow Breathe Easy' group was created. The group was officially launched in September 2009 by Ann Keen MP and Minister for Health and now meet once a month. Membership of the group is around twenty and increasing and there is a mixture of patients and their partners, carers, friends and BLF representatives. The Community Matrons are the named clinical leads, supported by the Partnership Manager. A speaker is invited to each meeting to discuss both health and social care, as well as local community interests. The group are also used as a consultative group for COPD pathways and other patient public involvement events and

consultations. They also lobby for the ongoing improvement of services for COPD, nationally through the BLF and locally through the NHS Primary Care Trust and local authority social care.

### Pulmonary rehabilitation

Pulmonary rehabilitation is highly rated by patients (NICE, 2004) and the BLF for its effectiveness in controlling COPD exacerbations and giving patients physical and mental health benefits. At the start of the project, the commissioning PCT in Hounslow did not have a dedicated COPD pathway; consequently most of the interventions for patients with COPD were provided through acute services and primary care, with Community Matrons supporting patients at home. If pulmonary rehabilitation was required by patients, it had to be accessed through an 'exceptional circumstances' procedure. Many patients were unaware that they could be referred; however, for those that were, the process involved the acute respiratory consultant contacting the patients' GP, who would then request the PCTs 'exceptional circumstances' panel to uphold the consultants' request that the patient would benefit from pulmonary rehabilitation. Although the decision outcomes were usually favourable, the patient would then be referred to an acute setting (usually where the consultant is based) to receive the intervention. The complexity of the process often resulted in a time lag which was frustrating for the patient.

One of the patient participants of the working group and the Breathe Easy group with advanced COPD, whose partner decided that the 'wait was too long' took up their concerns with the local MP, Ann Keen who was also the Health Minister. This proved to have a successful outcome, as the Health Minister/MP has become involved in championing improvements in local respiratory services.

### New COPD pathway – raised profile

Locally, over 2000 patients with COPD have been identified through their GP (NHS Hounslow Annual Public Health Report 2008/09) and it is likely that there are also unidentified sufferers. COPD has been identified as one of the high level target disease areas in the commissioning PCTs 2010 planned targets for their 5 year projections and this has contributed to a new COPD pathway being commissioned. Work carried out by the 'Taking Care of Myself' project will be central to this pathway together with a strengthening community services strategy to reduce admissions and re-admissions and include pulmonary rehabilitation.

### Conference presentations

The work to develop the self care management plan has been presented at two conferences; the International Development Practice 'Enhancing Practice' in Eindhoven, The Netherlands and the British Lung Foundation conference.

### Conclusion

Given the right tools and support, patients with long term conditions can increase their quality of life, be more independent and confident about making decisions on their health and social care. This project has shown how self care management plans can contribute towards patients with COPD achieving this. Health and social care professionals can support and enable self care by understanding that their role and that of the patient is a collaborative one, being aware that everyone involved in the patients' care has a contribution to make that will enrich the patient experience and quality of care.

This project has also demonstrated how stakeholders, both professionals and lay people can work inclusively and collaboratively towards achieving developments and improvements in healthcare practice that have a positive impact on patient care.

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### Further information

A copy of the Self Care Management Plan is available on the FoNS website: [www.fons.org](http://www.fons.org)

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 Editors: Kate Sanders and Theresa Shaw  
 32 Buckingham Palace Road  
 London SW1W 0RE  
 Tel: 020 7233 5750  
 Fax: 020 7233 5759  
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