GUIDELINES

Improving the experience of care for people using NHS services: summary of NICE guidance

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EDITORIAL by Eaton and colleagues

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Cite this as: *BMJ* 2012;344:d6422
doi: 10.1136/bmj.d6422

This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

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Previous articles in this series

- Improving the experience of care for adults using NHS mental health services (*BMJ* 2012;344:e1089)
- Diagnosis and management of the epilepsies in adults and children (*BMJ* 2012;344:e281)
- Donor identification and consent for deceased organ donation (*BMJ* 2012;344:e341)
- Assessment and referral after emergency treatment of a suspected anaphylactic episode (*BMJ* 2011;343:d7595)

The emphasis in healthcare has often been on clinical efficacy and outcomes, which can come at the expense of the patient's experience. Developments in healthcare delivery can make giving attention to the individual more difficult, especially as healthcare has become more technological and specialised, increasing the number of people and services that a patient has contact with. Changes in the working practices of healthcare staff (such as more part time working) and the rise in the number of large institutions delivering care can mean that patients have less opportunity to develop relationships with professionals who treat them and are more likely to be treated by a team.

The NHS "next stage" review, a review commissioned to develop a vision of an NHS fit for the 21st century, recognised the experience of patients as one of three dimensions of quality.[1] The other two dimensions were clinical effectiveness and safety. This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) on improving patients' general experience of NHS care.[2] The recommendations are for all settings and all who use adult NHS services and cover mainly the interactions between healthcare staff and patients, and aspects of organisation.

Recommendations

Recommendations in this guidance were developed using published NICE guidelines, systematic reviews in areas viewed as a priority by the Guidance Development Group (GDG), and the GDG's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in italic in square brackets.

Essential requirements of care

- Do not discuss the patient in their presence without involving them in the discussion. [*Based on the experience and opinion of the GDG*]
- Be prepared to raise sensitive issues (such as sexual activity, continence care, and end of life) as these will not be raised by some patients. [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Ensure that the patient's nutrition and hydration are adequate at all times (when they are unable to manage this themselves) by:
  - Providing regular food and fluid of adequate quantity and quality in an environment conducive to eating
  - Placing food and drink where the patient can reach them easily
  - Encouraging and helping the patient to eat and drink if needed
  - Providing appropriate support, such as modified eating aids and/or drinking aids.

  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Ensure that the patient's pain relief is adequate at all times when they are unable to manage their own analgesia by:
  - Not assuming that the patient's pain relief is adequate
  - Asking the patient regularly about pain
  - Assessing pain using a pain scale if necessary
  - Providing pain relief regularly and adjusting as needed.

  [*Based on the experience and opinion of the GDG*]
- When the patient is unable to manage their own personal needs (for example, relating to continence, personal hygiene, and comfort), inquire regularly and try to meet such needs at the time of asking. Ensure maximum privacy.
  [*Based on the experience and opinion of the GDG*]

Shared decision making

- When trying to reach a shared decision on investigations and treatment, discuss the matter in a style and manner that enables the patient to express their personal needs and preferences. [*Based on the experience and opinion of the GDG*]
- Give the patient the opportunity to discuss their diagnosis, prognosis, and treatment. [*Based on the experience and opinion of the GDG*]
- Before starting any investigations or treatment:
  - Explain the medical aims of the proposed care
  - Openly discuss and provide information about the risks, benefits, and consequences of the investigation or treatment (taking into account factors such as coexisting conditions and the patient's preferences)
  - Set aside adequate time to allow any questions to be answered, and ask the patient if they would like a further consultation.

  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Clarify what the patient hopes the treatment will achieve and discuss any misconceptions.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Give the patient, and their family members and/or carers if appropriate, adequate time to decide whether they wish to have investigations and/or treatment.
  [*Based on the experience and opinion of the GDG*]
- Accept and acknowledge that patients may vary in their views about the balance of risks, benefits, and side effects of treatments.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Use the following principles when discussing risks and benefits with a patient:
  - Personalise risks and benefits as far as possible

Fig 1 | Personalised pictogram and bar chart based on high quality predictive models showing that of 100 patients with particular clinical characteristics 49 will experience a cardiovascular event (such as a heart attack or stroke) over the next 10 years. Adapted with permission from the Institute of Health and Society, Newcastle University

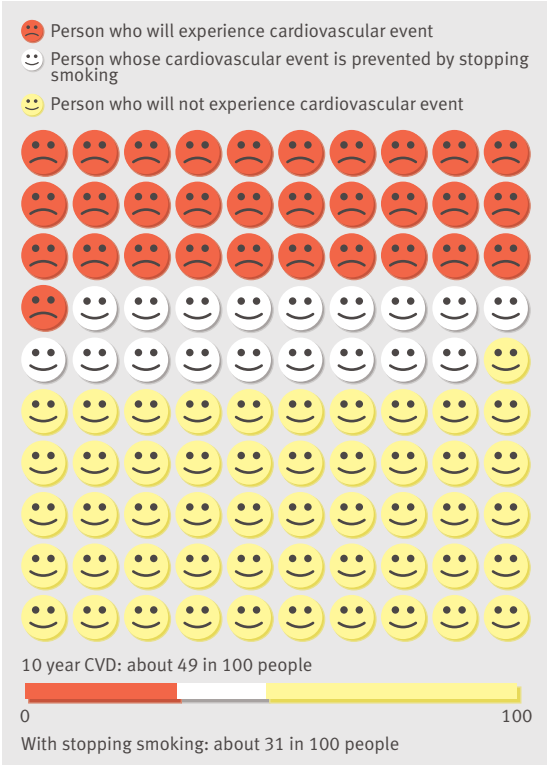

Fig 2 | Personalised pictogram and bar chart showing the likely reduction in risk of cardiovascular events after stopping smoking, reduced from 49 in 100 to 31 in 100. Adapted with permission from the Institute of Health and Society, Newcastle University

– Use absolute risk rather than relative risk—for example, the risk of an event increases from 1 in 1000 to 2 in 1000, rather than the risk of the event doubles
– Use natural frequency rather than a percentage—for example, 10 in 100 (better still, 1 in 10) rather than 10%
– Be consistent in the use of data—for example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5
– Present a risk over a defined period of time (months or years) if appropriate—for example, if 100 people are treated for 1 year, 10 will experience a given side effect
– Include both positive and negative framing—for example, treatment will be successful for 97 out of 100 patients and unsuccessful for 3 out of 100 patients
– People differ in the way they interpret terms such as rare, unusual, and common, so use numerical data if available
– Consider using a mixture of numerical and pictorial formats—for example, numerical rates and pictograms (such as figures 1 and 2).

[*Based on a high quality systematic review and the experience and opinion of the GDG*]

- Offer support to the patient when they are considering options. Use the principles of shared decision making:
  – Ensure that the patient is aware of the options available, and explain the risks, benefits, and consequences of these
  – Check that the patient understands the information
  – Encourage the patient to clarify what is important to them, and check that their choice is consistent with this.

  [*Based on the experience and opinion of the GDG*]
- Be aware of the value and availability of patient based decision aids. If suitable high quality decision aids are available, offer the most appropriate one to the patient.
  [*Based on systematic reviews and the experience and opinion of the GDG*]

Tailoring healthcare services to the patient

- At intervals agreed with the patient, review their knowledge, understanding, and concerns about their condition and treatments, and their view of their need for treatment, as these may change over time. Offer the patient repeat information and review, especially when treating a long term condition.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Tailor healthcare services to the patient's needs and circumstances, taking into account locality, access, personal preferences, and coexisting conditions. Review the patient's needs and circumstances regularly.
  [*Based on the experience and opinion of the GDG*]
- Give the patient information about relevant and available treatment options even if these are not provided locally.
  [*Based on the experience and opinion of the GDG*]
- Tell the patient about available health and social services (such as smoking cessation services) and encourage them to access these according to their individual needs.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Ensure that discussions are held in a way that allows the patient to express their personal needs and preferences for care. Allow adequate time so that discussions do not feel rushed.
  [*Based on the experience and opinion of the GDG*]

FURTHER GUIDANCE

The remit for this guidance was to make recommendations for improving patients' general experience of care throughout the NHS. Many of the areas important to patients concern interactions with staff rather than specific interventions. Inevitably many areas that are important for patients' experience are not covered. The guidance has not looked at the physical environment and access, and many groups of patients have needs beyond those that general guidance can cover. The guidance is not intended to cover aspects of patients' experience that may be particular to specific conditions. Those areas will continue to be considered in condition specific NICE guidance and quality standards.

Methods

To decide what to include in this guidance, the Guidance Development Group reviewed existing frameworks of patients' experience, results of NHS patient surveys, a high level scoping study of themes in studies of patients' experience commissioned from the University of Warwick,[7] and existing NICE recommendations. The group made recommendations for healthcare professionals and services under the following headings:

- Knowing the patient as an individual
- Essential requirements of care
- Tailoring healthcare services to the patient
- Continuity of care and relationships
- Enabling active participation in care.

The group conducted reviews of systematic reviews in the areas of decision aids, risk communication, continuity of care, and patient education programmes. Recommendations in other areas were informed by existing published NICE recommendations, the scoping study commissioned for the guidance development, and the group's experience and opinion.

The draft guidance underwent a reviewing process, in which stakeholder organisations were invited to comment; the group took all comments into consideration when producing the final version of the guidance. Further updates of the guidance will be produced as part of the NICE guideline development programme.

The Guidance Development Group recruited for this guidance consisted of a larger number of patient members than for a standard clinical guideline. The group consisted of six patient members and 10 members who are practising healthcare professionals and/or academics with an interest in the patients' experience.

- Clarify with the patient at the outset whether and how they would like their spouse, partner, family members, and/or carers to be involved in key decisions about the management of their condition.
- Accept that the patient may have different views from healthcare professionals about the balance of risks, benefits, and consequences of treatments.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Accept that the patient has the right to decide not to have a treatment (even if you do not agree with the decision) as long as he or she has the capacity to make an informed decision and has been given the information needed to do this.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- Inform the patient that they have a right to a second opinion
  [*Based on the experience and opinion of the GDG*]
- Respect and support the patient in their choice of treatment or decision to decline treatment.
  [*Adapted from existing NICE recommendations using the experience and opinion of the GDG*]
- When patients in hospital are taking medicines for long term conditions, consider and discuss with them whether they are able to, and would prefer to, manage these medicines themselves.
  [*Based on the experience and opinion of the GDG*]

Continuity of care

- Consider each patient's requirement for continuity of care and how that requirement will be met. This may involve the patient seeing the same healthcare professional throughout a single episode of care or ensuring continuity within a healthcare team.
  [*Based on the experience and opinion of the GDG*]
- Inform the patient about:
  - Who is responsible for their care and treatment
  - The roles and responsibilities of the different members of the healthcare team
  - The communication that takes place between members of the healthcare team.

  [*Based on the experience and opinion of the GDG*]
- Give the patient (and their family members and/or carers if appropriate) information about what to do and whom to contact in different situations, such as "out of hours" or in an emergency.
- For patients who need several different services, ensure effective coordination and prioritisation of care to minimise the impact on the patient.
  [*Based on the experience and opinion of the GDG*]
- Ensure clear and timely exchange of patient information between healthcare professional teams and other agencies—for example, transitions of care including discharge.
  [*Based on the experience and opinion of the GDG*]

Overcoming barriers

Many of the recommendations included in this guidance and its associated quality standards (statements and measure markers of high quality care) overlap with professionals' codes of practice and the standards to which most professionals and services aspire. Patient surveys and national reports, however, indicate that the experience of patients using NHS services is variable.[3 4] The NHS Confederation (an independent body that represents organisations providing and commissioning NHS services in England) suggests that a cultural shift is needed to ensure that the experience of patients shapes services.[5] The inclusion of patients' experience in the NHS Outcomes Framework (used for assessing NHS performance) and the requirement for services to assess and report their performance against these measures will encourage services to place greater emphasis on this aspect of quality. The NHS National Quality Board (NQB) has agreed on a working definition of patients' experience to guide the measurement of patient experience across the NHS[6]. Robust measures of the experience of patients still need development and validation to achieve this aim.

The members of the Guidance Development Group were Sophie Staniszewska (chair), Jo Adams, Eloise Carr, Miranda Dodwell, Christianne Forrest, Melanie Gager, Annette Gibb, Poonam Jain, David Martin, Tom McLoughlin-Yip, Alan Nye, Suzannah Power, Amanda Smith, Richard Thomson, Chandi Vellodi, Barrie White. Staff from the National Clinical Guideline centre who were involved in development of the guidance were Joanna Ashe, Liz Avital, Ian Bullock, Taryn Krause, Kate Lovibond, Norma O'Flynn, and Silvia Rabar

Contributors: NO'F wrote the first draft. Both authors revised the article and have approved this version. NO'F is the guarantor.

Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: NO'F is employed by the National Clinical Guideline Centre, which is funded by NICE; SS was commissioned by the National Clinical Guideline Centre to carry out a scoping study to inform the guideline and has received research grants from the Big Lottery Fund, the National Institute for Health Research Service Delivery and Organisation (NIHR SDO) programme, the UK Clinical Research Collaboration, and Macillan; no other relationships or activities that could appear to have influenced the submitted work.

Provenance and peer review: Commissioned; not externally peer reviewed.

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A PATIENT'S JOURNEY

Polymyositis

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Cite this as: *BMJ* 2012;344:e1181
doi: 10.1136/bmj.e1181

This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

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Previous articles in this series

- Juvenile myoclonic epilepsy (*BMJ* 2012;344:e360)
- Gambling addiction (*BMJ* 2011;343:d7789)
- Amyloidosis (*BMJ* 2011;343:d6326)
- Facial disfigurement (*BMJ* 2011;343:d6326)

A formerly active man who developed polymyositis at age 47 explains how this rare and debilitating autoimmune disorder has affected his life

LEARNING POINTS

Subtle features need to be recognised in the history because the presentation is not always textbook
Organise a muscle biopsy to confirm the diagnosis
Have a low threshold for referring to specialist centres for another opinion

Life before diagnosis

About two years before my diagnosis in 2006 I became progressively more tired. I was a farm manager, a physical, outdoor job, and was used to working long hours during busy periods. I began to find manual tasks increasingly tiring and found myself needing more sleep and waking up feeling less refreshed. This in turn affected my concentration and ability to plan my days effectively. Also, I would often come home and fall asleep before our evening meal, be woken by my wife to join the family for supper, and then either fall asleep in my chair again or go straight to bed. I found it increasingly difficult to have a social life, and, if I did make the effort, I was often too exhausted to enjoy it.

I had no pain and just put the symptoms down to ageing; I was 47 at the time. In July 2006 things came to a head: my work became too difficult to manage and my family life was reduced to saying "hello" and "good night." One night I came home with barely the energy to enter the house. I then realised that something must be seriously wrong. I told my wife I could not continue like this. She made an appointment for me with my general practitioner the following day.

My diagnosis, initial treatment and impact on my life

The GP ordered blood tests, which came back showing only a high creatine phosphokinase (CPK) level. This indicated that I might have had a heart attack, which did not fit with the rest of my symptoms. The doctor repeated the tests the next day and found that my CPK was even higher. I was admitted to the local hospital for further blood tests and an electrocardiogram. They were all inconclusive apart from the raised CPK. As my family has a history of rheumatoid arthritis, I was referred to a consultant rheumatologist.

Luckily at this time I had private health insurance with my job, and obtained an appointment the following week. Within the first few minutes of the appointment Dr Kaushik relayed his suspicions that I might have polymyositis. A muscle biopsy confirmed the diagnosis. At this time I was unable to work. Dr Kaushik prescribed a high dose of steroids to try to control the inflammation and I felt some improvement. However, with gradual reduction of the dose of steroids to a long term sustainable level, the tiredness returned. I was now also starting to feel more muscle fatigue and severe, sudden, cramp like pains that limited my mobility.

My family history

Predisposition to polymyositis and rheumatoid arthritis are thought to be hereditary. Environmental factors, such as shock or viral infection, are thought to act as triggers that cause the immune system to attack the body. It may be the same gene that causes both conditions and affects other factors that determine what is attacked by the auto-immune system. My father received a diagnosis of rheumatoid arthritis at age 32 and was severely physically affected by the condition all his life. My sister was diagnosed as having rheumatoid arthritis at 26 and her quality of life is severely restricted. In addition, both my daughters were diagnosed with juvenile arthritis as teenagers. The elder is now 23 years old and in full remission. The younger is 19 and takes methotrexate, which allows her to lead a normal life.

My early retirement

In 2007, after six months off work and on a high dose of steroids, starting at 40 mg and reducing slowly, I tried a gradual return to my job. I did mainly office work, initially for two to three hours a day. I steadily increased this to eight hours of light work. However, as soon as I reduced the dose of steroids to 10 mg the fatigue increased and limited me to moving slowly around the house.

Dr Kaushik and I developed a shared care arrangement between King's College Hospital in London, my local hospital, and my GP. This works well. I see Dr Kaushik every six months, although this appointment is often delayed by long waiting lists. If I have a flare up and need advice, I contact Dr Kaushik by phone or email and he fits me into his outpatient clinic, often on the same day. My visits to London vary from two-monthly to six-monthly, depending on my condition, potential changes in drugs, or the need to re-assess dosage.

My wife always accompanies me to my appointments. This is very important for both of us. When I am in pain, I

A CLINICIAN'S PERSPECTIVE

Polymyositis is an autoimmune condition characterised by inflammation in the muscles. It is rare, with an incidence of around five to 10 cases per million.[1] It most often presents between ages 30 and 60, with women being more affected than men in a ratio of 2:1. The usual presenting feature is weakness in the muscles. Initially the thigh and arm muscles are affected, leading to difficulties in rising from a low chair, climbing steps, lifting objects, and combing hair. Fatigue, muscle aches, and cramps may also be present. The symptoms can fluctuate, with good days and bad days.

The commonest finding on clinical examination is weakness in the larger muscle groups such as the quadriceps, with fairly preserved strength in small muscles such as those in the hands. Around a third of patients may have a rash, which can include a blue-purple discolouration on the upper eyelids, a flat red rash involving the face and upper trunk, or raised purple-red scaly patches over the knuckles. A rash suggests dermatomyositis.

The diagnosis is based on raised concentrations of muscle enzymes—such as creatine kinase, lactate dehydrogenase, transaminases, and aldolase—and characteristic mysositic changes on electromyogram. The diagnosis can be confirmed by a biopsy from an affected muscle that shows changes consistent with active inflammation. People with polymyositis have a 1.5-fold increase in the incidence of malignancy, compared with the unaffected population, and this problem is usually seen in the first two years of the diagnosis. Further investigations, such as computed tomography, may be needed to exclude a malignant condition.

Initial treatment of polymyositis is with steroids to control the inflammation in the muscles. This needs to be started as soon as the diagnosis is confirmed because "time is muscle"; the longer the delay in starting treatment, the lesser the chance of recovery. A high dose of steroid is recommended, calculated as 1-2 mg per kg of the patient's body weight. Later, patients are started on further treatments such as methotrexate or cyclosporine. In people with recalcitrant myositis, treatments such as intravenous immunoglobulins may be needed.

Diagnosis of polymyositis can be difficult and not everyone will present with classic symptoms. This was the case with Mr Truepenny. He had symptoms for longer than usual before presentation and his CPK was only moderately raised. However, his family history of various autoimmune conditions was compelling. My first priority was to arrange an urgent electromyogram and muscle biopsy before starting treatment. When the muscle biopsy came back conclusive I started him on high dose steroids. Recovery was slower than expected. Because this condition is rare, I decided to refer Mr Truepenny to a neuromuscular centre at Kings College Hospital for a second opinion. They agreed with the diagnosis and since then Mr Truepenny has been managed between the two hospitals.

Viswanath Kaushik

USEFUL RESOURCES

Myositis Support Group UK (www.myositis.org.uk)—UK charity specifically for the inflammatory myopathies: dermatomyositis, polymyositis, inclusion body myositis, and juvenile dermatomyositis. It aims to provide information to patients and their families, to help give them a better understanding of their illness, to relieve the isolation felt by an individual with a rare illness, to guide patients in the right direction for treatment, to raise awareness of the conditions, and to raise funds to promote and support research

The Myositis Association (www.myositis.org)—is an organisation in the USA that provides information, support, advocacy, and research for those concerned about myositis

The Cure JM Foundation (www.curejm.com)—was established in October 2003 with the goal of raising awareness of this rare disease and funding research to find a cure for juvenile myositis

find it difficult to concentrate, which can lead to confusion and misunderstanding that my wife can help clarify. She is the first person with whom I discuss illness related issues and she can then raise them during our consultations. The trips to London are not easy. They require early starts, an hour in the car to the local station, one hour on the train, and 30 to 50 minutes to get across London by bus.

In 2007, 12 months after my first visit to my GP and discussions with my family and my two consultants, I decided to retire on medical grounds. This was a very difficult decision as I had worked for the company for over 25 years. The house we lived in came with the job, so my retirement caused a big family upheaval. The overriding factors, after returning to work, were the pain, fatigue, and mental pressure it put me under. I was in no doubt that these would have affected my long term health and family life. Looking back, we took the right decision; it has allowed me to rest and make best use of my life with polymyositis.

My life after retirement

During the past four years my health has been very unpredictable. It was difficult to find the most effective drugs and dosages to control the disease and, just as importantly, to work out what my body can tolerate. Taking high doses of steroids for a year has resulted in a weight increase from 95 kg to a peak of 132 kg. This has made simple things difficult; for example, bending down to put on socks and shoes, sitting up from lying down, standing up from sitting and standing a short time. I am trying to lose weight but there is a limit to how little one can eat.

Over time I began to realise that with this unpredictable, chronic condition I have had to change my lifestyle. There are periods, sometimes days, sometimes weeks, when I feel well, my pain levels are low, and my fatigue is manageable; however, I have to be careful not to overdo things, or the pain and fatigue soon return. My main goal each day is to find a balance, to achieve as much as I can without overdoing it. During, what I call my "uphill with the hand brake on" days, everything is hard work. For example, simple activities such as showering and dressing can take up to an hour. I am determined not to spend the day in front of the television, but on the worst days that may be my limit. When "the hand brake is off" and the incline of the hill seems less, I try to keep myself busy. I enjoy outdoor photography and creating greetings cards for family and friends.

It is rewarding to find ways to make daily activities easier for myself. For example, a monopod takes the weight of my camera and helps keep it steady, and a walker with a seat allows me to rest. If I go shopping, I can sit down before I get too tired, which enables me to pace myself and do more. If we go out with friends on an "uphill" day, I take my wheelchair and they take turns in pushing me.

The support and understanding of my family are important to me. My wife is a rock and my daughters are great. They often take the brunt of my frustrations when pain levels are high and I become irritable. We have a great bunch of friends around us who always want to know how I am, involve me in their plans, and are aware of my limitations.

My advice to healthcare professionals

Six years on, I have developed a new approach to dealing with healthcare professionals: I now plan what my wife and I want to say when we go to our appointments. I have learnt that the more accurate the information I give medical and nursing staff the better they can understand and respond to my condition. I am not afraid to ask questions or ask for clarification. I now expect my consultations to be within an equal partnership. My aim is to help healthcare staff to understand me as a person and how this rare disease affects my life so that I can receive the best treatment and care available.

Competing interests: All authors declare no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Provenance and peer review: Not commissioned, not externally peer reviewed.

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Accepted: 25 November 2011