The patient's journey: multiple sclerosis

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Wenn einer eine Reise tut, dann kann er was erzählen

When someone goes on a journey there will be lots to tell afterwards, according to the above Austrian saying. This is how we feel about our description of the journey that is multiple sclerosis. We will not focus on its aetiology, diagnosis, or treatment, but we will concentrate on the experiences of a patient (MD), his wife (IL), and the impressions of one of their children (ML). Looking back on our journey together we will discuss and share our thoughts. A short description of our experiences at time of diagnosis (box 1) and a personal outlook on the future (box 2) are given here; a more detailed description of the journey is on bmj.com

The map

The map of the journey is characterised by good and bad news. The “companions” of the patient and their influence are most important. Our review therefore concentrates primarily on patients with chronic illnesses and their companions. In our opinion, their paths differ substantially, and their demands change during the course of the disease.

The good news

Benign courses without progression for a long time have been reported.^{1,2} Some patients do not have relapses for years, even without specific treatment. However, the clinical course of the disease is not predicted by particular clinical signs. It has as many different manifestations as there are patients. No one can say whether a particular patient would have done worse without therapy. Statistics of large trials are in favour of a substantial benefit for the patients who receive an immunomodulating treatment.

The bad news

Despite the progress in diagnosis, understanding of the pathomechanisms, and treatment, half of the patients with multiple sclerosis are forced to quit their jobs after 10 years of illness, owing to fatigue and neuropsychological disturbances. This puts an enormous psychological and social burden on the patients' families and a financial burden on the community.

The companions

For their hard and troublesome journey, the patients need many different, good, and loyal companions. We list the ones that we found most important in box 3.

The neurologist

For a patient with multiple sclerosis, the first companion is the neurologist who tells him or her the diagnosis. This is a crucial moment, the moment when the patient's journey begins (box 1). In our case, this was even more complicated because the patient was a medical professional. So when the neurologist told him the diagnosis, he felt as if the doctor was talking about someone else—something he was used to doing as part of his job. The patient didn't take in the diagnosis immediately. It seemed completely impossible to him that a disease could affect him. His sentiments were “confirmed” by the fact that the treatment was effective and he could leave the hospital only a few days later, apparently completely recovered.

To overcome this problem, the diagnosis should be told repeatedly, in several sessions. Doctors could ask their patients what they know about the disease, its treatment, or its sequelae. This should not end up in a conversation resembling a school examination but in a discussion among equals. Repeated telling of the diagnosis is important as denial is a coping mechanism that we have observed repeatedly in our years of medical practice.

The patient

During the night or when the patient is alone, he or she is the only companion. Multiple sclerosis often starts with unspecific complaints. In our particular case, it started with tingling sensations and numbness in the toes that later spread to the feet. The patient (MD) found it difficult to acknowledge the severity of the symptoms. Even telling the diagnosis to someone else—his wife—did not make the seriousness of the situation real to him. Not even the tears of one of his children made him accept his illness. Denial of the disease and positive thinking seemed to him the best way to overcome his problem. Society expects men to be strong. The patient did not want to give in.

His condition deteriorated severely, and within a few hours he could walk only when supported. Only then did he accept his situation.

Like most patients who are confronted with the diagnosis of a chronic illness, he began to think about sin and atonement. The timing of the diagnosis played a part in this; it was Good Friday. Religious conversion

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An extended version of the journey, with a reading list, is on bmj.com

Box 1: The diagnosis

MD: "Health is me," and disease existed only in my job as a clinical pathologist. Suddenly it started, with tingling sensations and numbness in my toes and later in my feet. After a magnetic resonance imaging scan my neurologist told me the diagnosis: multiple sclerosis. It seemed completely impossible that a disease could affect me. I had no time for such silly troubles. And indeed, after five days my stressful life continued. Four weeks later I felt dizzy. Within a few hours I could walk only when supported. My condition worsened dramatically. Suddenly I could not swallow any more. Now I realised I was ill and felt cheated by life.

IL: I had never before mentioned a girlfriend who had multiple sclerosis. Within three years, she had ended up in a wheelchair. Since then I had been afraid of getting multiple sclerosis too. When Marcus told me the diagnosis it hit me like a blow. Suddenly one of my nearest and dearest was affected. I had no time for a work-up process; things progressed too quickly. Only a few weeks after the diagnosis, Marcus's condition had become life threatening. I had no time for reflection and complaints about my fate. It was like a horror trip, an apocalypse. I was left alone, and had to get through it.

ML: I remember the onset of the symptoms well because of the regular phone calls with my extremely worried mum. We wondered what it could be, but we never really considered multiple sclerosis.

Knowing the diagnosis I had a vague idea of what lay ahead: a slowly progressive neurological disease that would probably end with Marcus needing a wheelchair. I tried to accept the disease. Being a strong family, we thought we were handling it quite well. Like mum, I remembered a friend of the family who had had an absolutely horrible time. I never expected the worst to hit us, but that was exactly what it did.

is common in people after receiving catastrophic news. Religiousness may even assume the role of a companion, although this is obviously not a solution for an atheist.

Box 2: The future

MD: I have learned that there are other priorities in one's life that are worth focusing on. I want to accumulate experiences and intellectual treasures. I am reading, reading, reading.

The ability to swallow came back: Nena had made *Polsterzopf* (a typical Austrian dessert). "Only chew them to get the taste," I tried, and suddenly the piece was gone and down in my stomach. It was like Christmas. Today my main problem is fatigue, and I feel crushed. When I was unable to swallow, I dreamt of eating *bollito* and drinking chianti at Nerbone's [restaurant in Florence] once more. I have done it. I can still do silly things such as going to Florence, strolling through the city, having some stops in bars for espresso macchiato or eating *bollito*.

Nobody can tell what the future brings. The malignant course of the disease is over, and it is now progressing more moderately. Despite the side effects I regularly receive my immunomodulating therapy. I am convinced that I will not have a relapse.

IL: Marcus's condition has stabilised, and things had to return to everyday life again. For me, it took two years to realise and accept the diagnosis as much as I can accept it at all. I regard complete acceptance as impossible or a sign of desperation.

Our everyday life is complicated by Marcus's abrupt emotional instability. Additionally he forgets things that are important to me. Though Marcus does not depend on a wheelchair any more we are not as mobile as before. I always have to consider that he needs regular stops and gets tired very quickly.

Every minute I am aware of a possible change for the worse. When Marcus does not call me at the usual time I am afraid. Sometimes I fear I will be left alone again. We try to remember the beauty and the pleasures of each moment. We don't let things slide any more.

ML: I admire my mum, in her way she was and is strong. On the other hand, I was feeling sorry for her—was there going to be a future for her and Marcus? The disease has been stable since then, and today, Marcus has "only" mild residuals. Although I know that the disease is never really under control, I feel optimistic and hopeful.

To this patient, the wheelchair did not seem to be the worst aspect of his illness. He has always found the idea of being unable to swallow much worse. The patient and his carers have different points of view on this. He felt socially handicapped by his inability to swallow as he had to spit his saliva into a handkerchief every five to 10 minutes. The need to adapt the family home, to make it suitable for someone with disabilities, may well have been the main reason for his wife to regard the wheelchair as the worst outcome.

Next of kin: the patient's wife

In contrast to the patient, his wife took in the diagnosis immediately. A female friend of hers had developed multiple sclerosis, and she had always been afraid of getting it too. At the time of diagnosis, the wife saw the disease more clearly than the patient himself. This difference in accepting the illness may be because the patient himself blocked out the diagnosis and kept pushing it away. For any patient, the most effective coping mechanism may be to deny the diagnosis and remain strong. Family members, however, are expected to show their emotions—otherwise they would appear to have a heart of stone.

During the acute phase of the illness, close relatives are often asked to give more support than a single person can provide. A patient's wife needs other companions—for example, the couple's children—to help her cope, physically as well as emotionally.

If the disease progresses fast close companions have no time for their own reappraisal process. The need to return to everyday life does not create time for this either. The result: repressed feelings. For relatives, the work-up or acceptance of the diagnosis therefore often takes longer than for the patient. Sometimes it is much harder for them to accept the illness at all.

After the acute phase, everyday life may be complicated by new problems that one would not think of immediately. We experienced fatigue, sudden emotional instability of the patient, more complicated ways of thinking, and sexual—and therefore emotional—problems.

Relatives and friends

Relatives and friends, such as the children of the patient's wife (who are not his own) often have a more rational view. They are not involved as directly and emotionally.

Their reaction depends on their experience and age. Younger ones tend to be more emotional, seeing primarily the threat of a disabled family member. Older ones may handle the situation more rationally. The coping process is more important to them.

The most important thing children can do is to support other companions. Looking back, they were the ones who helped the wife most. They provided new energy through their endless willingness to talk. The resulting discussions were an important coping strategy.

Doctors, nurses, therapists ...

In addition to doctors, many other medical professionals—such as physiotherapists, occupational therapists, speech and language therapists, and psychologists—participate in the management of

Box 3: “Companions” of patients with chronic illnesses

- General practitioner or clinical specialist
- Patient
- Next of kin (wife, children or parents) or friends
- Other relatives or friends
- Doctors, nurses, therapists, etc
- Colleagues in the workplace and other patients
- Companions that are not people: religion, hobbies such as music, books, etc

multiple sclerosis. These companions spend a lot of time with their patients, and sometimes emotional relationships develop.

In our experience, it is not only the quality of medical treatment that counts. The patient and the companions need a sheltered environment. Personal acquaintance with your doctors as colleagues does not guarantee this. Why some people can make you feel sheltered is unclear. To a large extent, however, this depends on the patient. One doctor or nurse gives you the impression that he or she is here to protect you and help you, and others do not. On discussing this with other patients it transpired that they prefer quite different doctors or nurses. In a sheltered and warm environment even treatments that are known to have many side effects may cause fewer undesirable ones.

Young patients, especially when they are still working, need available neurological rehabilitation units and preferably outpatient physiotherapy or occupational therapy. The preferable option would be for these therapies to be administered in the patient's home or workplace.

Colleagues in the workplace and other patients

Outside the hospital, support from social workers and work colleagues is of major importance. These companions are usually not medically or psychologically trained. It is often very hard for them to deal with a chronically ill colleague. In our society, success and output are all that count. Either someone can fulfil his or her tasks or that someone has to leave.

Regular work can provide life with meaning and can prevent people from sinking into depression and despair. Viktor E Frankl reported that it was the people who had nothing to live for who died most quickly in the concentration camps.³

Meeting other patients with similar diseases—such as can be found in self help groups—is undoubtedly helpful. The availability of self help groups or patients' organisations depends on the individual country. In some instances, however, those patients who always say that they have gone through an even worse time are boring. A patient who is not so lucky in regaining all his faculties fast feels like a failure, and an ungrateful one at that.

“Inanimate” companions

The internet provides a lot of information on the course, treatment, and other questions related to

multiple sclerosis (see Additional educational resources for patients).

A chronic disease causes changes in everybody's life. The patient therefore needs to change his or her attitudes and has to find other priorities on which to focus. In view of the patient's potential disabilities, their “inanimate” companions will be different from before the onset of illness. They may include religion or hobbies—for example, music or books—and others. They can also be helpful in reappraisal of life with the disease.

The decision: “ship or plane?”

Making a journey one is regularly confronted with the question: ship or plane? For multiple sclerosis, the answer is difficult. We can specify only what we would do or not do again in a similar situation.

We found the family of extraordinary importance in the acute stage of our patient's disease. The family gave him the safety and tenderness that hospitals cannot give. In such a safe environment, even things that one would believe impossible may happen. For example, our patient regained his ability to swallow when one of his children had made a dessert that he liked very much (box 2).

The whole time, the care that the patient demanded and his urge to regain his independence were opposing forces. It is important to balance life between the two opposites. It may have seemed cruel to the patient that we helped him regain independence, but it was necessary for his self esteem. How to do this depends on the individual situation, and everyone needs to find their own balance.

A chronic disease such as multiple sclerosis has an impact on every relationship. The experiences may lead to closer contact and more thorough understanding. On the other hand, motor dysfunctions and sexual disabilities as well as mental changes impose serious problems on a relationship. They may even lead to the couple drifting apart. After the acute stage of the disease the patient and the companions need to normalise their daily lives again. The companion needs to return to his or her former life on the basis of their experiences, which may lead to a total reassessment. For the patient, a completely new period starts. Patient and companions have differing views of the “normalised” life with regard to mobility, activities, or drive (see bmj.com).

The patient should regard the disease as a chance to focus on new horizons and meanings of life. This change of emphasis is very important. Hobbies like

Additional educational resources for patients

National Multiple Sclerosis Society (www.nationalmssociety.org)—informative, with several personal experiences

Multiple Sclerosis Society (www.mssociety.org.uk)—information for British patients

Multiple Sclerosis International Federation (www.msif.org)—multilingual information

MS Service Center (www.ms-service-center.de/msservice)—information for German patients

MSF (www.msfacts.org/donations.html)—clearly arranged and informative, with a lot of links

literature or music can give an optimistic attitude. Additionally one can consume as much as one needs at any time, and there is no danger of “burning someone out.”

Conclusion

The most important companions for a patient with multiple sclerosis are probably family members and friends. They can give practical and psychological support in daily life. However, these activities are an enormous effort for them, and they may be at risk of expending all their energy and ending up burnt out.

If a patient has a clear view of the map and has good companions such as family, friends, and hobbies, which constantly reinforce the good news, the journey will be more pleasant for the patient and his surrounding.

“There is nothing in the world, I venture to say, that would so effectively help one to survive even the worst conditions as the knowledge that there is a meaning in one’s life.”³

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Interactive case report

Postoperative hypoxia in a woman with Down’s syndrome: case progression

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This is the second of a three part case report where we invite readers to take part in considering the diagnosis and management of a real patient using the rapid response feature on bmj.com. In three weeks’ time we will report the outcome and summarise the responses

Last week (9 April, p 834) we presented the case of Miss Webb, who has Down’s syndrome and had a sudden postoperative deterioration in her condition after a hysterectomy for menorrhagia. We invited readers to comment on the ethical issues around surgery and the possible cause and management of her postoperative hypoxia.

Miss Webb’s chest radiograph

Results of laboratory analysis of pericardial fluid

Test	Result
Protein	53 g/l
Lactose dehydrogenase	383 IU/l
White cells	19×10 ⁶ /l
Lymphocytes	50%
Polymorphs	50%
Red blood cells	2.74×10 ⁹ /l
Bacterial growth	Negative
Acid-fast bacilli	Negative

Questions

- 1 What further investigations would you do?
- 2 What is the likely diagnosis?
- 3 How would you treat this patient?

Please respond through bmj.com, remembering that Miss Webb is a real patient and that she and her carers will read your response

We suspected a pulmonary embolism but her V/Q scan showed no abnormality. She then had echocardiography to investigate unexplained hypoxia and possible cardiomegaly seen in the chest radiograph. This showed a large pericardial effusion with a normal cardiac anatomy and function. A pericardial drain was inserted, and 1100 ml of straw coloured fluid was drained. The table gives the results of laboratory analysis of the aspirate. She made good progress immediately after the drainage of pericardial fluid and her oxygen saturation returned to normal. She was transferred to a medical ward after three days in the intensive therapy unit. One week later, repeat echocardiography showed only trivial pericardial effusion. She was discharged from hospital with a diagnosis of pericardial effusion of unknown cause.

One month later, she was readmitted to the hospital with gradually worsening shortness of breath, cyanosis, and one episode of loss of consciousness lasting for a few seconds. Clinically she looked very unwell. The figure shows her chest radiograph. Echocardiography showed the recurrence of a large pericardial effusion.

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