# Improving communication in the diagnosis of painful neuropathy

Kit McAuley

**Peripheral diabetic neuropathy is a distressing and disabling complication of diabetes, affecting up to 50% of older people with type 2 diabetes (Boulton, 2005). Careful assessment and questioning are essential for an accurate diagnosis. However, this can be severely hampered by communication difficulties such as language barriers, learning difficulties and hearing loss. This article describes the development of the Pain Pictures toolkit, which uses simple pictures to describe the typical symptoms of painful neuropathy in a format that is easily understood. Evaluation of the toolkit has shown it to be an effective and useful tool in the communication of chronic pain.**

**Article points**

1. Peripheral diabetic neuropathy is one of the most common complications of diabetes.
2. Careful assessment and questioning are essential for an accurate diagnosis.
3. Communication problems, such as language barriers, learning difficulties and hearing loss, can delay diagnosis.
4. "Pain Pictures" is a picture-based toolkit that was developed to help diagnose painful neuropathy in people with diabetes who find it difficult to verbalise their symptoms.
5. Evaluation of the toolkit has shown it to be a simple and effective means of communicating chronic pain.

**Key words**

- Diabetic neuropathy
- Diagnosing pain
- Communication
- Pain Pictures

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People with diabetes are particularly vulnerable to nerve and vascular anomalies of the legs and feet. Peripheral diabetic neuropathy is perhaps the most common complication of diabetes (Kumar et al, 1994), and its prevalence appears to increase with age and duration of diabetes. Neuropathy can affect up to 50% of older people with type 2 diabetes (Boulton, 2005).

Painful diabetic neuropathy has been described as a distressing and disabling complication. It is well known that chronic pain from symptomatic diabetic neuropathy can impair quality of life in people who experience it, and that it has significant effects on emotional reaction, energy, physical mobility and sleep (Benbow et al, 1998; Galer et al, 1999) and can be difficult to treat.

Careful assessment and questioning are essential for an accurate diagnosis. Communication difficulties, such as language barriers, learning difficulties and hearing loss, can lead to a delay in obtaining an accurate diagnosis, causing the individual further unnecessary discomfort.

To improve communication in the diagnosis of painful neuropathy, Enfield PCT Diabetes Nursing Team developed a picture-based toolkit in collaboration with a pharmaceutical company. The toolkit, termed "Pain Pictures – A Better Picture of Chronic Pain", is a simple but innovative concept. Its main function is to help diagnose painful neuropathy in people with diabetes who find it difficult to verbalise their symptoms.

Painful neuropathic symptoms are not exclusive to diabetes, but, for the purpose of this article, the focus is on the specific needs of people with diabetes who have neuropathy. This article describes the development of the Pain Pictures toolkit, and its evaluation by healthcare professionals and people with diabetes.

**Page points**

1. In September 2006, Enfield PCT set up a neuropathic assessment clinic in line with Standard 11 of the Diabetes NSF.
2. At the same time, the PCT developed a care pathway (updated in May 2008) that includes treatment guidelines for painful neuropathy.
3. However, before treatment can be given it is essential to have an accurate diagnosis.
4. The diagnosis of painful diabetic neuropathy is reliant on clinical judgment, physical examination and a thorough consideration of the history and the patient's experience of pain.

## Enfield demographics

Enfield PCT is situated in north London, 12 miles from the city centre. It has a population of 280 000, of whom 11 920 are currently on the diabetes register. The prevalence of people with diabetes varies from practice to practice. The lowest prevalence in a GP practice is 2%, and the highest is 7.4% (average 4.1%; Quality and Outcomes Framework Database, 2008). The average national prevalence is 3.86% (Diabetes UK, 2008).

Enfield has a diverse population. In the 2001 Census, 38.8% of the population were from minority ethnic backgrounds (Office for National Statistics, 2001). The top four non-English languages spoken by Enfield pupils in 2008 were Turkish (9.59%), Somali (2.99%), Greek (2.50%) and Bengali (2.22%; Enfield Observatory, 2008). People from ethnic minority groups have a higher prevalence of diabetes than white Europeans (Riste et al, 2001) and this is reflected in the active caseload.

The estimated percentage of people in Enfield over the age of 50 was 29% in 2006. Life expectancy for men is 77 years, and for women 81 years (Enfield Observatory, 2008). These data are of significance when considering that the prevalence of diabetic neuropathy increases with age (Young et al, 1993) and duration of diabetes.

## Tailoring diabetes services

In line with National Service Framework Standard 11 (Department of Health [DH], 2003), the author's diabetes nursing team has endeavoured to:

> ***"Develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of diabetes receive timely, appropriate and effective investigation and treatment to reduce their risk of disability and premature death."*** (DH, 2003)

One example of how the author's PCT has tailored diabetes services to reflect this advice is the establishment of a neurovascular assessment clinic in September 2006. The clinic was set up to ensure that people with painful neuropathic symptoms have access to care that is systematic, evidence-based and of high quality (McAuley, 2008). Practice teams can refer people to this service, and the current waiting time to first appointment is 2 weeks.

In September 2006, the author's team also developed a care pathway that includes treatment guidelines for painful neuropathy. The care pathway was updated in May 2008, and is currently under review for circulation to primary healthcare teams in April 2009.

Progress continues to be made in the treatment of symptoms found in painful diabetic neuropathy. Indeed, care pathways have been developed countrywide to ensure that people who experience painful symptoms have access to systematic treatment programmes that reflect current treatment recommendations (National Collaborating Centre for Chronic Conditions, 2008). However, before painful neuropathy can be treated, it needs to be identified.

## Diagnosis of diabetic neuropathy

The diagnosis of painful diabetic neuropathy is reliant on clinical judgment, physical examination, and a thorough consideration of the history and the patient's experience of pain (Argoff et al, 2006).

Symptoms that people typically describe during assessment are varied and can include any of those listed in *Box 1*. This core set of commonly described symptoms has been reflected in the neuropathic pain symptom inventory, and these descriptive terms have been found to span multiple cultures (Crawford et al, 2008). This is not an exhaustive list of possible pain descriptors, but are the symptoms most commonly reported; they occur mainly in the legs and feet, and increase in severity in the late evening and at night (Watkins et al, 1996).

The management of diabetes (and the diagnosis of painful neuropathic symptoms) can be especially difficult when communication issues are present (Greenhalgh, 2008). Examples of difficulties that can be

**Box 1. Common symptoms of painful diabetic neuropathy.**

- Numbness
- Tingling
- Shooting
- Prickling
- Pins and needles
- Aching
- Dullness
- Burning
- Buzzing
- Coldness
- Sharp pains
- Electric shocks
- Knife-like/stabbing

encountered include language barriers and assessing people with learning difficulties, hearing deficits or speech impediments.

Since it was set up in September 2006, 163 people have been referred to the neurovascular clinic. This financial year (ending April 2009), 69 appointments have been offered to people from ethnic minority backgrounds. During these appointments, a common theme began to emerge – that communication about painful neuropathic symptoms, even in the presence of an interpreter, is difficult.

## Development of the toolkit

In May 2008, as the lead healthcare professional in the neurovascular clinic, the author, in conjunction with a pharmaceutical company, decided to look at ways of improving patient care in her PCT. She thought about what could be done to make the most effective use of her clinical time, and to ensure that people with diabetes who had problems with communication could access the correct treatment pathways at the earliest possible opportunity.

The author envisaged a toolkit that used simple pictures to describe the typical symptoms of painful neuropathy in a format that could be understood by anyone. This would be used in conjunction with a further set of pictures that enabled the person with diabetes to communicate sites, times and severity of pain to the clinician tasked with

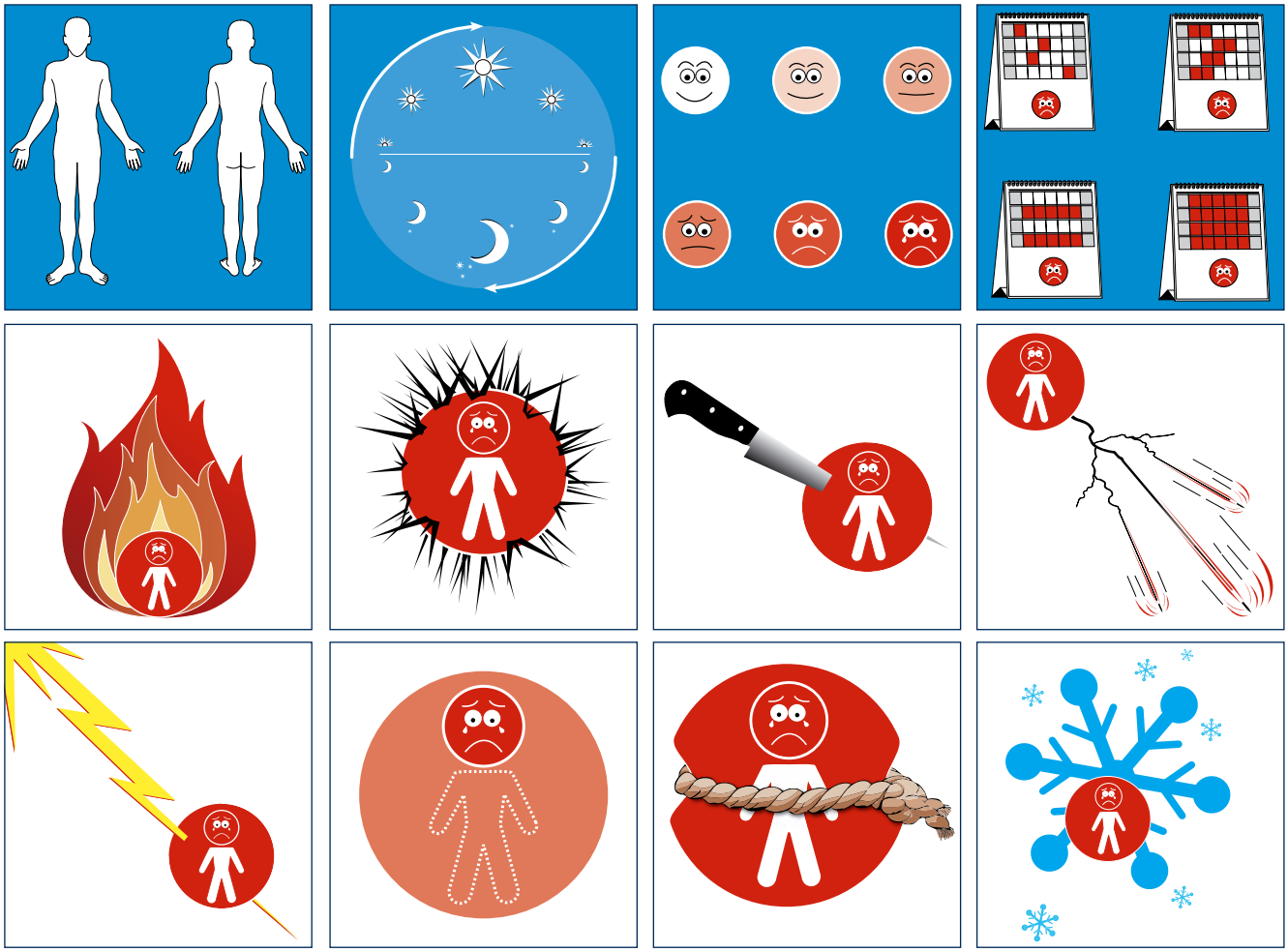

*Figure 1. Sample pictures from the Pain Pictures toolkit. Top row, from left to right: body picture, to point out site of pain; day/night, to point out when pain is present; severity of pain; calendar for communicating how often pain is present. Middle row, from left to right: burning pain; prickly pain; stabbing pain; shooting pain. Bottom row, from left to right: shock-like pain; dull/numb pain; tightening/squeezing pain; cold pain. Reproduced by kind permission of Pfizer.*

**Page points**

1. The author envisaged a toolkit that used simple pictures to describe the typical symptoms of painful neuropathy in a format that could be understood by anyone.
2. It would be used in conjunction with a further set of pictures that enabled the patient to communicate sites, times and severity of pain to the clinician tasked with the diagnosis.
3. The first prototypes for the Pain Pictures were evaluated by healthcare professionals from a variety of settings: a consultant physician, diabetes nurse specialists, vascular nurse specialists, podiatrists, practice nurses and GPs.

the diagnosis. A variety of different ways of putting together a picture-based toolkit were discussed, from using picture boards through to flip boards.

Some adjustments were made to the initial set of assessment cards that were developed, and further discussions took place regarding the format and packaging. To ensure ease of use, it was decided that the final product would be printed on coated or laminated cards that could be held together by a round paper clip, which would enable the user to either open the pictures up and lay them on a table, or to flick through them with ease.

A further meeting was held with the final draft, and a user guide was formulated. Within weeks the first prototypes were made available for evaluation (*Figure 1*). It was decided that the toolkit would be evaluated by healthcare professionals from relevant disciplines across the primary care and specialist settings. The evaluators were approached from a variety of different settings: a consultant physician, diabetes specialist nurses, vascular nurse specialists, podiatrists, practice nurses and GPs. A total of 10 evaluations were undertaken.

## Results of the evaluation

The healthcare professionals were asked to rate various parameters for the toolkit on a scale of 1–10 (1=strongly disagree; 10=strongly agree). The average scores are shown in *Table 1*.

The results of the initial evaluation have been very promising. The toolkit was found to be relatively easy for the evaluators to use with people with diabetes, especially when they could not speak English well.

It appears that the usefulness of the toolkit was inclusive of both sexes as well as with cultural groups. The evaluators felt strongly that the picture cards may help to ensure that people would be able to access treatment for painful neuropathic symptoms sooner. The individuals who used it were reassured that their symptoms were outlined in the toolkit.

## Patient feedback

The patient experience of using the Pain Pictures appeared to be very positive. Some of the comments from people with diabetes who helped to evaluate the Pain Pictures are reproduced below:

> ***"Pictures are a good description of how I feel."***

**Page points**

1. Feedback from people with diabetes who used the Pain Pictures during the evaluation was very positive.
2. In particular, some felt very reassured that their main symptoms were "common" enough to be described in the Pain Pictures toolkit.
3. The toolkit appeared to be most useful in primary care where there may be reduced access to translation services.

*"They help me describe how my legs feel."*

*"This is a good idea."*

*"A picture paints a thousand words!"*

*"Very useful description."*

*"A good prompt."*

*"It is nice to know that it is not in my head and that these pains are real."*

*"I feel listened to now and someone is taking an interest."*

At the time of writing, the author is launching Pain Pictures across the Trust to ensure that all healthcare teams have access to this tool. The Trust plans to re-evaluate the toolkit at 6 months, when it will send out an evaluation questionnaire to all practices who used the toolkit.

Patient experience of the toolkit will also be gauged further in the neurovascular assessment clinics at appointments where link workers have been booked to help translation. It is hoped that these evaluations will be able to influence further improvements to the toolkit.

In a more recent development, the symptom description pictures are being used in posters that will be distributed to all surgeries, pharmacies and podiatry clinics to publicise neuropathic pain symptoms and how to access treatment. The PCT's care pathway was updated in May 2008, and is currently under review for circulation to local Primary Healthcare Teams in April 2009, and reference to the Pain Pictures toolkit will be added.

## Conclusion

Evaluation of the toolkit in the current format shows that the Pain Pictures are a useful tool in the diagnosis of neuropathic pain, especially when communication difficulties are present. It appeared to be most useful in the primary care setting where there may be reduced access to translation services.

Positive feedback from patients was also noted. A salient point was that some of the people with diabetes who used the tool during the evaluation felt very reassured that their main symptoms were "common" enough to be described in the Pain Pictures toolkit.

Although the toolkit was generally regarded as an effective and useful tool to aid communication of chronic pain, further work to improve some of the pictures, as well as further additions, are planned for the future.

An example of a relevant addition that may be needed, in order to fully reflect the Leeds Assessment of Neuropathic Symptoms and Signs (S-LANNS) questionnaire for the

**Table 1. Results of evaluation of the Pain Picture assessment cards by healthcare professionals.**

| Parameters evaluated | Average score* |
|---|---|
| The toolkit is very easy to use with patients | 7.4 |
| The toolkit is essential when dealing with patients who cannot speak English | 8 |
| The toolkit has helped my patients to describe their pain | 6.6 |
| The toolkit can be used with any patient of any age | 8.5 |
| The toolkit can be used with any patient of any nationality | 8.7 |
| The toolkit can be used with both male and female patients | 9.3 |
| I have been able to diagnose chronic pain more quickly in the consultation using the cards | 7.2 |
| I have felt more confident in the diagnosis of chronic neuropathic pain when I have used the cards | 7.1 |
| I feel that I have a much better picture of my patients' pain having used the cards | 7.8 |
| The use of cards in general practice would mean that patients get the right treatment sooner | 9.7 |

*On a scale of 1–10 (1 = strongly disagree; 10 = strongly agree)

diagnosis of painful diabetic neuropathy, is a picture to illustrate "jumping" sensations (Bennett et al, 2005). The pain scale used in the Pain Pictures will be translated into a quantifiable pain scale. ■

***A poster presentation outlining this project was showcased at the Primary Care Diabetes Society meeting in Birmingham in November 2008 and was awarded second place.***


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