

# Volunteers: Making the most of them

Jill Rodgers

## Article points

1. Volunteers are involved in many different aspects of diabetes care and support.
2. NHS trusts have a statutory duty to involve people with diabetes in the planning, delivery and evaluation of local diabetes services.
3. Volunteers can feel disadvantaged when working in a healthcare environment, and steps need to be taken by all involved with them to ensure that any disadvantages are minimised.
4. Actively welcoming and supporting the work of volunteers will help their roles be as effective as possible.
5. If volunteers are involved in a local initiative, ensuring their role is clear to them and others will help them to work most effectively.

## Key words

- Volunteers
- Support groups
- Service users

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2005 was the Year of the Volunteer, indicating a general recognition and valuing of the role of volunteers, not just in health care. Volunteers are being increasingly involved in many areas of health care, including diabetes care. Their role can be misunderstood, taken for granted or even seen as unwelcome. In this article, Jill Rodgers shares her experiences of how volunteers, often people living with diabetes, can contribute to and enhance diabetes care provision, and how health professionals can make use of their skills and also help them reach their potential.

Nurses working in diabetes may have had personal experience of being a volunteer, or know others who have taken on this role, which may help with their understanding and recognition of the importance of this role.

Locally, volunteers may be involved in many aspects of diabetes care. For example, they may play a part in running a local support group, which will often (though not necessarily) be affiliated to Diabetes UK, the national charity for diabetes. Support groups are often formed by people who have identified their own need to meet with other people with the same condition. Some have regular meetings with invited speakers on various diabetes-related topics, while others might have more informal meetings for people to talk and share their experiences, and some simply offer telephone support. Local support groups should be able to provide their contact details so that they can offer support and help to people seen by nurses in consultations and structured education programmes.

## Providing emotional support

The Diabetes UK Listening Project (Diabetes UK, 2001) identified that many people have anxieties at the time of diagnosis, and having

the opportunity to talk to others with diabetes and to acknowledge the emotional impact of their diagnosis was seen as a gap in service provision. To meet this need, Diabetes UK, in conjunction with the Department of Health (DoH), has provided training and support materials for people with diabetes to run specific sessions to help others talk about their emotions in the first 2 years after diagnosis. The locally run support sessions have been evaluated and have been shown to help people cope with their diabetes, and they have also provided a focus and structure for local volunteers to help others with diabetes (Walker et al, 2005).

The sessions are known as '3D' (Diabetes, Diagnosis, Discussion), and provide an opportunity for people to talk and share experiences, but do not offer any medical advice or formal education. The people who run these sessions – either people with diabetes or their carers – have voluntarily given their time to attend a residential training weekend and also to organise and run the support sessions locally. The sessions are not available in all parts of the country, but local Diabetes UK voluntary groups or members of local specialist diabetes teams can help to identify if 3D sessions are available in particular areas.

### Providing input to local services

Another role of volunteers is that of providing service user representative views to their local diabetes service, network or primary care trust. *The NHS Plan* (DoH, 2000) highlighted the need to ensure that the voices of service users were listened to, including contributing to changes and improvements to NHS services, and this has been reinforced in the recent white paper *Our health, our care, our say* (2006b).

In 2001, Section 11 of the *Health and Social Care Act* (DoH, 2001) placed a statutory duty on NHS trusts to consult with services users not only at every stage of service planning, but also when delivering and evaluating services. All trusts will have a named patient and public involvement manager – or someone with a similar title – to ensure that this happens, both in diabetes and in other disease areas. Hence, it is likely that most local planning groups or networks have at least one person living with diabetes who is involved.

Alternatively, or additionally, trusts may have a ‘diabetes service user group’ that puts collective views forward regarding new ideas for service development, as well as considering information provided from local planning groups. This group then reports back to the local diabetes planning group or network.

The volunteers providing service user representation can offer a valuable insight into the impact of service developments on people who will access the services. This helps to ensure that any new service development will benefit service users. Diabetes UK has been running training sessions during 2005 and early 2006 to help service users to be more aware of NHS developments and changes in diabetes, and also to help them to be as effective as possible in their local roles. Similar training programmes are available for different specialties – for example, for people with heart conditions (British Heart Foundation, 2006).

Volunteers may also be involved in helping health professionals to have a greater

understanding of what it is like to live with diabetes, either by speaking at local meetings or by taking part in local diabetes education courses. In some areas, they are also involved in teaching on local structured education programmes for people newly diagnosed with type 2 diabetes (Arundel et al, 2003). Other roles include:

- helping in diabetes clinics
- running awareness-raising stands at local events
- collecting donations for Diabetes UK
- being participants in research projects
- campaigning and lobbying (both locally and nationally) for better services for people with diabetes.

Many of the volunteers have also attended an Expert Patients Programme (DoH, 2006a), which helps them not only to better manage their condition, but also to develop assertiveness skills that benefit them in many ways. Moreover, some of the attendees go on to be trained to run the Expert Patients Programme themselves, which adds to their skill set.

### How do people become volunteers?

When people are asked about how they first started in their voluntary roles, they will, in the author’s experience, provide answers such as:

*‘I’m not sure – my doctor thought it might be a good idea’*

*‘Well I went to one meeting and then got asked to another – and another after that’.*

Or, similarly, having been participants in one research project they may then be identified as a possible participant in the next one.

Many volunteers are recruited because they are quite vocal about services, making them likely to participate in activities and have an effective role. Volunteers often say that when they have ‘volunteered once’, they are asked to take on another voluntary role. For example, the chair of a Diabetes UK voluntary group

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1. As their roles expand, many people report that their voluntary work becomes similar to a full-time job.
2. In their voluntary roles, people with diabetes often encounter the very professionals who provide their diabetes care, which may result in their next consultation focusing on their voluntary work rather than their diabetes.
3. If volunteers are involved in any local initiatives it tends to be at the convenience of health professionals.
4. Volunteers may find it difficult to understand the NHS and how budgeting systems work, or get caught up in jargon that means little to them.

may be invited to sit on a sub-group of the local diabetes network, or give a presentation for a health professional study day.

As their roles expand, many people report that their voluntary work becomes similar to a full-time job – only without the pay! In the light of this, there is increasing recognition that reimbursement of expenses should be a minimum requirement, and consideration should be given to offering payment to volunteers for their input, the author feels.

**Experiences of being a volunteer**

The experiences of volunteers in the NHS are both positive and negative: in some cases they are made very welcome in meetings and seen to be part of the team, while in others they may encounter hostility and suspicion and can feel excluded by health professionals (Walker, 2005). One volunteer commented to the author:

*‘I sometimes feel I’m just a “token” representative, so that a box can be ticked.’*

Another comment was from a volunteer who often felt excluded from discussions:

*‘I’m often “talked at” rather than “talked to”.’*

There are some inherent difficulties attached to the role. For instance, in their voluntary roles, people with diabetes often encounter the very professionals who provide their diabetes care, which may be disempowering or may equally result in their next consultation focusing on their voluntary work rather than their diabetes. Also, if volunteers are involved in any local initiatives it tends to be at the convenience of health professionals. For example, if a volunteer is asked to attend a meeting that is held during office hours, he or she might have to take time off work to attend.

Volunteers often have busy professional lives, and people who have had experience of being a volunteer will know how difficult that

can be in addition to employed work. While meetings during the evening might be more convenient to the working population, these can be difficult to attend for older people or those with young families. If volunteers are relying on public transport, some venues may be difficult for them to access.

It can be argued, particularly for people who act as service user representatives or provide an insight into living with diabetes for a local training course, that there is an unequal relationship between them and the health professionals. For instance, they may have been invited to sit on a sub-group but not previously have been involved or have no real idea of how or why the sub-group has come about, and also may have not had their role clearly defined. They may find it difficult to understand the NHS and how budgeting systems work, or get caught up in jargon that means little to them. One volunteer commented to the author:

*‘Why do we have to have so many words for kidney disease? I’ve heard it called kidney disease, renal disease, nephropathy – why not have just one term?’*

This highlights the fact that health professionals often use different terms when talking to colleagues from those that they use when talking to people with diabetes. While attempts may be made to adopt commonly used terms at meetings where people who are not health professionals attend, it is all too easy to fall into using the words spoken on a daily basis in discussions with other health professionals.

The other main difficulty reported by volunteers is that of gaining access to the systems that are easily accessible to health professionals:

- they may not have access to internal email systems
- they may not see reports circulated internally
- they may not be aware of a local initiative that health professionals are aware of.

Therefore, volunteers can find that they have to ask for information at meetings rather than be provided with it in advance.

Also, travel expenses for meetings are not always very forthcoming. The author has heard people making comments such as

*'Haven't you got a bus pass?'*

*'Well yes, we can pay your travel expenses, but I'm not sure how... there isn't really a system for you.'*

All this contributes to volunteers potentially feeling devalued in their roles and increases the feelings of inequality between them and the health professionals who they are trying to help.

### **So what do volunteers think?**

Despite some of the negative aspects outlined above, on the whole volunteers have an overwhelming enthusiasm for their role and are extremely keen to ensure that their contribution of any sort is valuable. They will often go above and beyond the call of duty to ensure that they can be effective, and they gain great satisfaction in being able to do something positive.

Volunteers are also extremely aware of the financial constraints placed upon the NHS and appreciate the time and effort that health professionals put in to provide their diabetes care, including giving their own time without additional reward or pay. There is an acceptance that volunteers often find themselves in situations where they may be overawed or feel less able to contribute fully than a health professional, but this in no way dims their enthusiasm in trying to work towards further improving the lives of people with diabetes.

### **How can health professionals make better use of volunteers?**

Diabetes UK (2005) recommends that service user representatives have their role defined, possibly by using a job or role description, to ensure that both they

and others are clear about what they are there for.

Health professionals may need to acknowledge that they sometimes have anxieties that arise from involving people with diabetes in some planning or education initiatives. The health professionals may not be sure how to develop a good working relationship, and they can be concerned about whether these volunteers will adequately represent the views of people with diabetes. Health professionals may need to work on overcoming their own fears (and sometimes prejudices) in order to treat these volunteers with the same respect that they would accord to their professional colleagues (Walker and Rodgers, 2003).

If volunteers are trying to raise local awareness of an opportunity to attend an open day or support group, they might want to come to their local diabetes clinic or put a poster up in their surgery waiting room. Receiving help and support from health professionals means that their initiatives are available to many people with diabetes, and helps people registered with surgeries to meet a wider range of people with diabetes and discuss their fears and concerns, as identified by the Listening Project (Diabetes UK, 2001).

Similarly, volunteers may have been asked by a diabetes network or planning group to obtain the views of people with diabetes about a specific issue, and again may need the help of health professionals in finding people with diabetes to talk to. One way to help them, for instance, would be to use existing NHS systems, such as enclosing questionnaires or information about how to contribute to a survey when routine NHS appointment letters are sent out. It is worth remembering that the responsibility to consult and gather public views on services lies with the NHS, not with volunteers living with diabetes.

The DoH (2006c) recommends that people asked by health professionals to contribute should be reimbursed for any expenses incurred in their role.

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2. Volunteers appreciate the time and effort that health professionals put in to provide their diabetes care, including giving their own time without additional reward or pay.
3. Diabetes UK recommends that service user representatives have their role defined, possibly by using a job or role description, to ensure that both they and others are clear about what they are there for.
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1. For health professionals who are working with volunteers, making sure that travel expenses are routinely offered for any work they may do, and also being aware of any additional costs they may be incurring (such as for stationery or postage), will help them feel valued.
2. Volunteers are now a vital part of many diabetes services, providing a welcome addition to the help and support provided by primary care and other staff.
3. Health professionals need to recognise the enormous scope of the role of volunteers today, and to welcome and appreciate their input.
4. If health professionals want to provide good diabetes care, understanding what it is like to live with the condition and what service users think of diabetes care is an essential part of ensuring that services meet their needs.

**Table 1. Ways in which healthcare professionals can make volunteers feel valued at meetings.**

- One of the key contributions that health professionals can make to ensuring volunteers feel valued is to create an environment that makes them welcome.
- Providing a warm greeting when volunteers attend a local diabetes network or planning group meetings, and ensuring everyone introduces themselves at every meeting, can help to make them feel part of the process.
- Ensuring that volunteers are aware of meeting dates well in advance, and providing them with an equal chance to contribute (including ensuring they know how to get an item put on the agenda), can enhance their perception of being valued. It can be of benefit to make sure that volunteers have access to the same information that others attending the meeting have, and that any information provided either is jargon-free or has a glossary to help people who are not health professionals to understand the terms used.

Making sure that travel expenses are routinely offered, and also reimbursing any additional costs for any work they may do (such as for stationery or postage), will help volunteers feel valued. Several ways in which healthcare professionals can make volunteers feel valued at meetings are highlighted in *Table 1*.

Health professionals may need to think twice about how they recruit volunteers, trying to get as wide a representation as possible, rather than focusing on the one or two individuals that have been identified locally as being willing to help. Ensuring that health professionals do not overburden volunteers will help them feel that they are not being taken for granted.

**Conclusion**

Volunteers are now a vital part of many diabetes services, providing a welcome addition to the help and support provided by primary care and other staff. Health professionals can help volunteers to understand their role and responsibilities and how they can help with service planning and delivery, so that their role can be maximised. Understanding what it is like to live with the condition and what service users think of diabetes care is an essential part of ensuring that services meet their needs. ■

Arundel F, Craddock S, Skinner TC, Graham W (2003) An all day workshop for people newly diagnosed with type 2 diabetes. *Journal of Diabetes Nursing* 7(7): 262–4

British Heart Foundation (BHF; 2006) *Make Yourself Heard - Hearty Voices*. BHF, London. [www.bhf.org.uk/heartyvoices](http://www.bhf.org.uk/heartyvoices) (accessed 03.07.2006)

Department of Health (DoH; 2000) *The NHS Plan: a plan for investment, a plan for reform*. DoH, London

DoH (2001) *Health and Social Care Act*. DoH, London

DoH (2006a) *Expert Patients Programme*. DoH, London. [http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/HealthInPartnership/UKNHSPolicy/UKNHSPolicyArticle/fs/en?CONTENT\\_ID=4128025&chk=3x48Wq](http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/HealthInPartnership/UKNHSPolicy/UKNHSPolicyArticle/fs/en?CONTENT_ID=4128025&chk=3x48Wq) (accessed 03.07.2006)

DoH (2006b) *Our health, our care, our say: a new direction for community services*. DoH, London

DoH (2006c) *Reward and recognition: The principles and practice of service user payment and reimbursement in health and social care*. DoH, London

Diabetes UK (2001) *Needs of the Recently Diagnosed: Listening Project 2001*. Diabetes UK, London. Available at <http://www.diabetes.org.uk/infocentre/reports/listening.doc> (accessed 03.07.2006)

Diabetes UK (2005) *Guidance for Primary Care Trusts (PCTs) and Diabetes Networks: User Involvement and the Diabetes National Service Framework (NSF)*. Diabetes UK, London. Available at <http://www.diabetes.org.uk/sharedpractice/documents/download.asp?lvid=1225&id=1247> (accessed 03.07.2006)

Walker R (2005) User involvement in diabetes care: A contemporary perspective. *Journal of Diabetes Nursing* 9(6): 204–5

Walker R, Rodgers J (2003) It's good to talk. *Diabetes Update* (Autumn): 17

Walker R, Rodgers J, Martin J, Williams C (2005) Training people living with diabetes to facilitate meetings to help people recently diagnosed with diabetes to discuss their feelings and experiences: the Diabetes UK '3D' (Diabetes; Diagnosis; Discussion) Pilot Project. *Diabetic Medicine* 22(Suppl 2): P373