

Improving supported self-management for people with diabetes

November 2009



Contents

Foreword	3
Scope	4
About self-management	6
Finding out what people with diabetes want	9
High quality, tailored information	10
Access to structured education	11
Personalised care planning	12
Support from peers, family and friends / Emotional and psychological support	14
Access to healthcare professionals and trained specialist advice when required	16
Barriers to supporting self-management	17
Conclusion and priorities for action	20
Further information	22

Foreword

There are over two and a half million people in the UK with diabetes. By 2025 it is estimated that this number will rise to over four million.

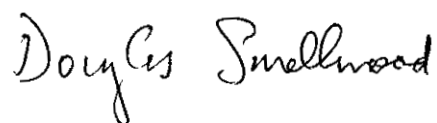
While this statistic is concerning for the simple reason that more people will be living with diabetes, it also has huge implications for the levels of care, services and support that will need to be provided in order for those people to live with and manage their diabetes.

Because *living* with diabetes is just that. People with diabetes only have contact with a healthcare professional for a few hours per year. The rest of the time they care for and manage their diabetes themselves. It is estimated that 95 per cent of diabetes management is *self*-management.

Self-management means that people have to make choices and decisions about how to manage their life and their diabetes. Through good self-management, people with diabetes can improve their quality of life and reduce the risk of developing complications. It can also help to prevent hospital admissions, or make those times when they do need to go into hospital, for whatever reason, a better experience, with a reduced length of stay.

To enable people to self-manage well requires support. What type of support people need will vary depending on how they are managing or whether they feel the need to access that support. The important thing is that the support is there.

In this document we look at what we consider are the essential components that make up good supported self-management. While there are many things that enable people to self-manage, we have outlined what should be provided at the very least. Whether this is good quality information for someone who has been recently diagnosed, or the knowledge that someone is on the other end of a telephone to offer advice for someone with established diabetes, it is vital that people are able to manage their lives with diabetes, rather than because of it.



Douglas Smallwood
Chief Executive, Diabetes UK

Scope

People with diabetes have to manage their condition on a day-to-day basis, with the support of their healthcare professionals, their families, friends or other carers.

In this document, Diabetes UK examines supported self-management and how the further development of self-management, education and care planning will enable people to better manage their lives with diabetes.

Background

The UK is facing a huge increase in the number of people with diabetes. Since 1996 the number of people diagnosed with diabetes has increased from 1.4 million to 2.5 million. By 2025 it is estimated that over four million people will have diabetes.

Most of the increase in cases will be Type 2 diabetes, because of our ageing population and rapidly rising numbers of overweight and obese people. The figures are alarming and confirm that diabetes is one of the biggest health challenges facing the UK today. If we are to curb this growing health crisis and see a reduction in the number of people dying from diabetes and its complications, we need to increase awareness of the risks, bring about wholesale changes in lifestyle, improve self-management among people with diabetes and improve access to integrated diabetes care services.

Good diabetes management has been shown to reduce the risk of developing complications, enhance quality of life and reduce hospital admissions. But when diabetes is not well managed, it is associated with serious complications including heart disease, stroke, blindness, kidney disease, nerve damage and amputations leading to disability and premature mortality.†

Many people with diabetes may only have contact with a healthcare professional for a total of a few hours per year, the rest of the time they care for and manage their diabetes themselves. Health services in the UK need to do more to support people with long-term conditions to help them to self-manage. They need to focus on prevention and early intervention and to ensure that services are developed around the needs of people with diabetes, rather than people having to fit in with what is available to them.

What is diabetes?

Type 1 diabetes develops if the body cannot produce any insulin. Insulin is a hormone which helps the glucose to enter the cells where it is used as fuel by the body. Type 1 diabetes usually appears before the age of 40. It is the least common of the two main types and accounts for around 10 per cent of all people with diabetes.

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). In most cases this is linked with being overweight. This type of diabetes usually appears in people aged over 40, though in South Asian and Black people, it can appear from the age of 25. It is becoming more common in children and young people of all ethnicities. Type 2 diabetes accounts for around 90 per cent of people with diabetes.

† *Diabetes in the UK 2009: Key statistics on diabetes*

About self-management

What is self-management?

Supported self-management and self-care are terms to describe how a person living with a long-term condition controls their condition and health themselves.

- Self-care is what each person does on an everyday basis, but which may be more difficult for a person living their life with a long-term condition.
- Self-management is the process by which a person develops the skills to manage their condition.
- Support for self-management and self-care is the responsibility of health and social care providers and is often provided by unpaid carers.

Successful self-management requires knowledge about the condition, how it needs to be treated and what needs to be done. This might also include behaviour changes and learning problem-solving skills and how to cope when things go wrong or become more difficult. It is essential that information about the condition, education and training is a key component of the self-management approach. It also needs to be recognised that people who have more than one long-term condition will need the information, skills and training to manage the different needs of their conditions.

The key self-management activities specific to diabetes care and living with diabetes are:

- managing the relationships between food, activity and medications
- self-monitoring of blood glucose, blood pressure and having retinal screening carried out
- targeting goals tailored to individual need, for example around footcare, weight loss, injection technique and self-monitoring activities
- applying sick day rules when ill, or what to do if going into hospital
- understanding diabetes, what care to expect and how to access services
- managing acute complications – hypoglycaemia and hyperglycaemia
- understanding legislative issues such as those related to employment and driving.

Why is supporting diabetes self-management important?

Approximately 95 per cent of a person with diabetes' management is self-management. Living with diabetes means just that, that diabetes becomes part of a person's life. Once a person has been diagnosed with diabetes, their life goes

on, and diabetes management has to 'fit in' with whatever else is going on in their life. Supporting self-management of people with long-term conditions can lead to positive outcomes such as:

- fewer primary care consultations, reduction in visits to outpatient departments and A&E
- reduced length of stay when in hospital
- better communication between professionals and patients
- behaviour change leading to a healthier lifestyle
- better symptom management resulting in a reduction in pain, stress, anxiety, depression and tiredness
- improved feelings of wellbeing and coping skills
- improved quality of life and health outcomes
- improved understanding of the person's own condition
- greater independence and increased patient satisfaction.

The majority of people living with diabetes want to maintain an independent, healthy and active life and if they need support to achieve this, it should be widely available. However, self-management does not mean that people are left to do everything on their own, but that health and social care professionals, peers and family members help to provide relevant and tailored support.

People with diabetes make decisions every day about what they eat, what and how much activity to undertake, how they will react to certain situations or stresses and if and when they will take their medications.

Supported self-management is about enabling people to have the confidence and skills to better deal with their diabetes, and forms a key part of the wider programme for supporting people with long-term conditions, including structured education programmes, the provision of high quality information, care planning and peer support.

Supported self-management policy in the UK

Self-managing on a day-to-day basis is a key part of good diabetes care. Once diagnosed, people with diabetes and their families need support to come to terms with the condition. They also need to learn the skills that will allow them to take control, and which contribute to the long-term reduction in risks associated with diabetes. How they do this and the support required will vary from person to person.

In England, Wales and Scotland, Service Frameworks set out the standards required for the health of people with diabetes, and to reduce inequalities in access to care. The frameworks provide a structure in which to promote the integration of high quality diabetes services and self-management. Similarly, all nations are aiming to shift the focus of care of complex long-term conditions towards primary or community care, to be more accessible to the people who access it.

In Northern Ireland, the last strategic guidance that related to diabetes was the CREST Report of 2003. Diabetes currently sits on a shortlist for consideration for a Service Framework.

The NHS Next Stage Review, published in 2008, describes a health service for England that supports greater active involvement in self-care to help prevent ill health and support people with health conditions to have the best quality of life possible. It outlines that everyone with a long-term condition has a personalised care plan and that services are organised around the needs of individuals. *Your health, your way – a guide to long-term conditions and self care* was published by the Department of Health in November 2008. It draws together information that already exists to help provide people with long-term conditions information about choices, support networks, and the tools and skills they can access to be able to fully engage in discussions about their care, and is designed to complement the personalisation of care, choice and effective care planning.

Support for self-management in Scotland has been mainstreamed in terms of Government policy within the Better Health, Better Care Action Plan launched in 2007 and the publication of the Self-management Strategy (Gaun yersel) in 2008.

In Wales, the National Service Framework Standard 3 requires that all people with diabetes receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle.

In Northern Ireland, the Department of Health, Social Services and Public Safety's Twenty Year Vision published in 2005 indicated that service users should play a central role in managing their own long-term chronic conditions. In the Department's 2005 Primary Care Strategy – *Caring for People beyond Tomorrow*, it was proposed that people be helped to acquire basic skills to help them manage any chronic conditions. The Service Framework for Cardiovascular Health and Wellbeing (2009) includes a standard that all patients with diabetes should have access to education about their condition, as well as emotional and psychological support.

Finding out what people with diabetes want

This document has been informed by a focus group and a series of surveys conducted last year.

Focus group and surveys

In February 2009, the focus group involving people with diabetes explored some of the key components that can enable people to successfully self-manage. The group looked at high quality, consistent information about diabetes, structured education for both the newly diagnosed and people with established diabetes and care planning. The group considered how these tools need to be in place and how they need to be presented to people with diabetes to help them gain knowledge about self-management. They also looked at making decisions around how they self-manage, who to involve and how the tools help their diabetes management. Their views are incorporated into the findings below.

- Access to healthcare services – Diabetes UK Primary Care Trust and Local Health Board Progress Survey 2008 (2008 Local progress)
- Diabetes UK survey of people with diabetes and access to healthcare services 2009 (includes the views of adult and children and young people members of Diabetes UK) (2009 Member survey)
- Diabetes UK short survey 2009 (Non member short survey)

Elements of self-management

While supported self-management is made up of many different components, Diabetes UK has identified the essential elements that people with diabetes need to be able to access, and what it considers to be the minimum services that need to be in place to ensure that people are supported to self-manage. These have been categorised as:





High quality, tailored information

Surveys showed that high quality information for newly diagnosed people was seen as crucial. It was important for this information to be produced and made available in different formats to suit people's varying needs, such as written (books, leaflets), visual and/or electronic formats (DVDs, computer technologies) or verbal (telephone helplines or face-to-face support). Verbal communication is particularly important as often written information isn't enough, and needs to be supported by contact with healthcare professionals. Diabetes UK research has shown that information from healthcare professionals is the most trusted source. In particular, the need for information to be put into context was raised as a key part of enabling people to self-manage. Examples of this included information about test results and the use of self-monitoring where appropriate, so that people with diabetes are not only informed of what tests are required and what their results are, but what those tests actually measure, what the results mean and what effect they will have on the person's management and the actions they take as a result. These were seen as important for people who had been recently diagnosed and for people with established diabetes.

Key survey findings

2008 Local progress

Just under half of Primary Care Trusts (PCTs) in England have a programme in place to raise awareness of diabetes in the general population. Of those, just over half differentiate between Type 1 and Type 2.

Over 60 per cent of PCTs require that information is available at the time of diagnosis, which includes Diabetes UK information, while 15 per cent require that information is available at the time of diagnosis, which may not include Diabetes UK information.

In Scotland, just over half of people with diabetes access the Diabetes UK website for up-to-date information. The same number reported seeking information from their healthcare professional, while just over a third sought up-to-date information on diabetes from the internet.

All Health and Social Care Trusts in Northern Ireland that responded to the survey ensure that information on diabetes is available at diagnosis, which includes Diabetes UK information.

In Wales, over three-quarters of Local Health Boards (LHBs) provide information at the time of diagnosis, which includes Diabetes UK information.

2009 Member survey

Over half the people diagnosed in the last 12 months had little or no awareness of the symptoms of diabetes prior to being diagnosed.

2009 Children and young people member survey

Over three-quarters of children and young people surveyed were able to find up-to-date information when they wanted it.

Non member short survey

Just over half of people asked knew something about diabetes before being diagnosed.

Nearly three-quarters of people asked said they were given information, however just under two-thirds found the information useful.

Of the people who said they had never received information, all said they would like to have had something.

Conclusions

Many people are given, or are able to access, information about diabetes, however there remain gaps in the provision of the essential information that people need when they are diagnosed.



Access to structured education

After information, access to structured education was discussed as one of the most important things that could contribute to effective self-management. Structured education, either in group or individual formats, has specific aims and learning objectives, which are shared with people with diabetes, carers and their families. While there are established, nationally recognised structured education programmes, there are also tools available to enable local health service providers to deliver programmes to meet local need, ensuring that they meet the requirement of structured education for diabetes.

Key survey findings

2008 Local progress

In England, three-quarters of PCTs said that they provide structured education that meets national guidelines for people with Type 2 diabetes, and two-thirds said they provide structured education for people with Type 1 that meets the national guidelines.

In Wales, those figures for LHBs are 100 per cent and 90 per cent respectively, and half of them also provide structured education for children and young people with Type 1 that meets national guidance.

In Northern Ireland, structured education was provided in four out of the five Trusts.

The Better Diabetes Care survey in Scotland showed that nearly two-thirds of people with diabetes had never been offered a place for a diabetes education session.

2009 Member survey

Just over a third of members said they had attended some kind of course since they were diagnosed.

Of those who hadn't, almost half said they would like to attend a course to learn more about how to manage their diabetes.

2009 Children and young people member survey

Only 25 per cent of children and young people had been on a course to learn about managing their diabetes (an increase from 11 per cent in 2006).

Non member short survey

Just under two-thirds of non members said they had been on a course or had been offered a course of some kind.

Conclusions

While more people have reported that they have been offered courses or have attended a course, there remain areas where there is still no provision of structured education, or limited access to courses.



Personalised Care Planning

The care planning process (currently being piloted as part of Diabetes UK's Year of Care Project) is centred around making routine consultations between clinicians and people with long-term conditions work as a partnership. It ensures that people get to discuss both the clinical and personal issues relating to their diabetes management. Care planning as a joint process between people and their healthcare professionals is seen as the perfect opportunity to agree goals and provide support to achieve personal action plans around diet, and physical activity, for example. It was here that the focus groups thought test results and clinical measures needed to be put into context. They suggested that for their annual review (annual diabetes checkup) to be a real opportunity to discuss their self-management goals with their healthcare professional, people should be able to choose to access test results before their appointment, and discuss them.

Key survey findings

2008 Local progress

Around half of PCTs in England require personal care plans to be agreed with people with newly diagnosed diabetes (this has decreased from two-thirds requiring this to be in place in 2007).

In Wales, over three-quarters of LHBs require that personal care plans are agreed with people with diabetes, and over half have trained all their healthcare professionals in care planning.

In Northern Ireland, two out of three Trusts that responded provide 24 hour telephone support, personalised care planning and training of healthcare professionals.

2009 Member survey

Around two-thirds of members said they had discussed their goals in caring for their diabetes in the last 12 months. Only about a third of people were given their test results before their annual review.

2009 Children and young people member survey

When children and young people were asked about the extent to which they had been able to talk about goals around caring for their diabetes, 39 per cent said almost always, 41 per cent said some of the time and less than 20 per cent said rarely or not at all.

Non member short survey

Over two-thirds of respondents felt confident or very confident in how they manage their diabetes. While not asked specifically about care planning, anecdotal evidence suggested that they felt more discussion and agreement was needed between themselves and their healthcare professionals. They listed monitoring, maintaining a healthy diet and exercise, blood pressure and blood glucose monitoring targets in particular.

Conclusions

Although some progress is being made in involving people in the management of their diabetes through care planning, there is still some way to go before care planning is available to all as an integral part of their care process. Training for healthcare professionals needs to be in place to ensure that they are able to support care planning.



Support from peers, family, friends and carers Emotional and Psychological Support

The ability to self-manage also includes how people are supported by peers, family and carers. The opportunities to learn and discuss how to manage diabetes with structured education and the care planning process should also be open to family, friends and carers. This means they are better placed to support the person with diabetes and be involved in their lifestyle changes, which can help prevent the person with diabetes feeling isolated and also helps integrate self-management into their home and social life.

The provision of emotional and psychological support should be an integral part of a diabetes service. Emotional and psychological needs of a person with diabetes have to be properly assessed in partnership with the person as part of the care planning process. It is important that people are made aware of the support available, so that they are able to choose if and when they need to access it. Structured education programmes should incorporate an emotional wellbeing component to raise awareness of a service that is often invaluable. While peer support helps a person's emotional wellbeing in an informal way, having a formal system or process in place is essential to ensure the right type of support is provided.

Key survey findings

2008 Local progress

From Diabetes UK's report *Minding the Gap* (2008) it was found that 85 per cent of people with diabetes in the UK have no defined access to psychological support and care, and at best only local generic services. Less than a third provided telephone advice and waiting times for less urgent/routine cases were unacceptably long. Only 2.6 per cent of services complied with all relevant National Service Framework and National Institute for Clinical Excellence guidance, and 25 per cent did not comply with any of them. Barriers to provision included lack of training and psychological input. Levels of provision varied between nations, with Northern Ireland having the highest and Wales the lowest level of provision.

Nearly two-thirds of PCTs in England said that psychological support is provided for people over the age of 16. Two-thirds said that psychological support is provided for children and young people under the age of 16 years. This builds on previous years and shows an improvement, but still needs to be improved further.

Just under a fifth of PCTs require general diabetes 24 hour telephone support to be available for newly diagnosed people.

2009 Member survey

Less than half of members said they would have liked to talk to someone about their feelings to help them cope with diabetes. For those who would have liked to speak to someone, a selection of preferences were noted including: 87 per cent for a healthcare professional, 12 per cent for family, 10 per cent for friends and 9 per cent for a support group.

Of those who wanted to speak to a healthcare professional, three quarters were able to.

2009 Children and young people member survey

Half of children and young people responding said they wanted to talk to someone in the last year, for example if they were upset or feeling unable to cope with their diabetes. Most children and young people wanted to talk to family members. For those who would have liked to speak to someone, a selection of preferences were noted including: 64 per cent for family, 35 per cent for a healthcare professional, 27 per cent for friends and 8 per cent for a support group.

Non member short survey

Respondents gave a range of answers in regard to coping methods, which included looking for information on the internet, reading books about diabetes, contacting Diabetes UK (using its information or accessing the website) and talking to friends or family.

There were no instances of people accessing support groups or tailored support.

Conclusions

Although provision of emotional and psychological support is available in some areas, more needs to be done to ensure that services are more widespread, and that people are able to access the services when they need to, and at a level of intervention that meets their needs.



Access to healthcare professionals and trained specialist advice when required

Many people in the focus group said that one of the most important things for people with diabetes is the ability to contact a trained person for advice when they need it. For those that have this access it is seen as an essential service. Being able to discuss thoughts or ideas, or to ask for advice in times of doubt or difficulty was reported as contributing directly to the success of their self-management.

Key survey findings

2008 Local progress

Less than a fifth of PCTs in England require 24 hour telephone support to be available for newly diagnosed people (same as 2007 but less than 2006).

In Wales, 30 per cent of LHBs require 24 hour telephone support to be available for people with diabetes.

In Northern Ireland, two out of three Trusts that responded provide 24 hour telephone support.

2009 Member survey

Less than a third of members had the contact number of a doctor or nurse that they could contact about their diabetes out of hours (ie on weekends and after 6pm on weeknights).

2009 Children and young people member survey

85 per cent of the children and young people felt they were able to talk to any of their diabetes team for advice and support outside of their appointments, 6 per cent were unable to and 9 per cent didn't know

Conclusions

Access to advice, help and support on demand is an integral part of good self-management for many people with diabetes. Accessing this support could mean the difference between a person being able to manage a situation themselves and having to travel somewhere for out of hours treatment or advice. Actual levels of provision are low in a service that is perceived as essential.

Barriers to supporting self-management

There are a number of potential barriers to self-management. People may not be able to access the information, resources or services that will enable them to develop their self-management skills, or the actual services and information may not be available.

Physical barriers include the nature of their condition or conditions where people have different needs. For example, the symptoms or treatment of one condition might affect how they are able to manage other conditions. Some people may find it very difficult to change their long-established behaviours in order to self-manage and will require a great deal of ongoing support, which needs to be available.

Financial or logistical barriers include physical limitations of access to services, time and locations, financial cost, local availability of services and ongoing support once people have had self-management training or guidance.

System barriers include conflicting advice or a lack of collaborative working between healthcare social care professionals in providing 'joined up' information, services and ongoing support for self-management. The structure of 'once a year only' reviews also works against self-management, as people can benefit from seeing their healthcare professionals on a more regular basis.

Those providing services need to make sure that support for self-management and specific support relating to diabetes is available in order to provide choice. Some

// My GP doesn't think monitoring is important. It's like trying to create order out of chaos, so I find workshops and discussion more helpful. //

Respondent to a 2009 Diabetes UK survey

people may benefit more from general support for self-management through courses such as the Expert Patient Programme, but condition-specific support is also needed and all people with diabetes can benefit directly from diabetes-specific support. It is also vital that the development of local services to support self-management includes the views and opinions of people with diabetes. Options are needed so that people can choose what is best in meeting their individual needs, and promoting these options locally could help people to decide.

Financial barriers also exist, for example a lack of government support, as funding for providing these education and support services is reliant on Strategic Health Authority, Health Board and Primary Care Organisations (the organisations that fund and commission local health services). It is also possible

// The Diabetes Specialist Nurse asked me about helping her to deliver a course to newly diagnosed people, but this has no funding and hasn't happened two years later. //

Respondent to a 2009 Diabetes UK survey

that these services may have been put in place in some areas, but are not measured effectively to show whether they are meeting people's needs.

Another potential barrier is resistance to change on the part of healthcare professionals, many of whom have been traditionally trained to deliver care to their patients; different skills are needed to effectively support people living with long-term conditions such as diabetes. Although healthcare professionals may see value in helping people to self-manage, it can cause conflict between people with diabetes who want to do things for themselves and healthcare professionals who feel they are responsible for these things, or in some cases do not agree with them.

Part of the process of supporting self-management involves healthcare professionals increasing their own skills and confidence in understanding what self-management means, so they can learn to support people with diabetes more effectively. The delivery of high quality and supportive care needs to be supported by training programmes that will enable professionals to work and make decisions in partnership with people with long-term conditions.

There can also be resistance to change from people living with diabetes. Over a lifetime of living with diabetes, it is likely that at some point a person may not want or be able to self-manage. The level of support to self-manage will vary according to what people want or what they feel they need, and some people may engage in some parts of the self-management process and not others as it suits them. Healthcare services have tended to create a culture of dependency, which can mean that some people either

// It took a long time to diagnose, even though I had symptoms. More info is needed on dietary advice – people don't know about low carbs etc, GP info is patchy at best. //

Respondent to a 2009 Diabetes UK survey

// I was asked to go to the blood pressure clinic but I don't go, I think it's all to do with budgets and targets – why go to two different clinics? //

Respondent to a 2009 Diabetes UK survey

feel that they can't or don't need to contribute to their own care. Engaging with people in programmes to enable self-management from the onset of their diabetes could help to change this mindset and increase people's participation in their own care.

As described earlier, the ability of people with diabetes to self-manage may depend in part on the support of their family or friends. In addition, unpaid carers may sometimes be unable to provide appropriate support to self-management, for example due to other demands on their time or problems with their own health. Effective partnership working and communication between the person with diabetes, their health professionals and/or local social care services will ensure that these individual situations are recognised, and that support could be put in place if it became necessary.

Supported self-management for children and young people

The majority of published literature reporting on self-management approaches is targeted at adults. While a small number of self-management and education courses for children and young people are available in various parts of the country, there are no established courses aimed specifically at children and young people and further research and development is needed in this area.

Structured education – delivered to a group, a family or an individual – should be available to support children and young people with diabetes, particularly as they approach the age when they transfer to adult services. Within the Children and Young People's Member Survey, a quarter said that they had attended a course, however from the sample size this only equates to around 165 children.

Conclusion and priorities for action

For people with diabetes, the healthcare services they access need to provide a high quality, consistent and caring environment that fully supports them to self-manage their condition.

This support should be flexible in its provision and made available to people in a way that fits in with their lifestyle and needs. All people with diabetes will need to understand the care to expect throughout their life, and their role in managing their own diabetes. It is the role of those working in healthcare to support this. Diabetes UK supports the recommendations made by the Diabetes Education Network in its report *Structuring diabetes services to support self-management* to achieve this goal.

The design of services needs to be based on the principle of putting the person with diabetes at its heart, and it is from within this person-centred infrastructure that a truly supportive and collaborative process will develop and evolve.

Diabetes UK has identified areas for action that, if taken, would ensure that the essential components are in place to enable people with diabetes to self-manage, with the ongoing support they need, if and when they need it. It is vital to develop systems to support good self-management, and for these actions be carried out without delay. Investing in the development of services and infrastructure to support self-management now will help to improve people's lives and yield benefits in the future. These areas for action are aimed at Government, primary care organisations, commissioners and providers of health services, as well as the partners they work with to provide services for people with diabetes.

Areas for action

- 1 Prioritisation by Government, Health Boards, LHBs and PCTs of self-management and approaches to delivery including:
 - provision of and signposting to tailored information and awareness programmes in varying formats
 - structured and regular diabetes-specific and general self-management education for people with newly diagnosed and established diabetes
 - enhanced partnership working and goal setting through care planning, including contextualising tests, measurements and self-monitoring
 - making results available to people before their appointments
 - improved access to emotional and psychological support including encouragement to access peer support
 - appropriate access to self-monitoring equipment and education to help people with diabetes interpret and use results.

- 2** Delivery of programmes and practices that empower and enable individuals to move from passive recipients to active partners in their own health and healthcare.
- 3** Establish the baseline of current provision, through local needs assessment and service mapping, and regularly monitor the experiences of people with diabetes regarding the quality of support provided locally for self-management and whether this informs local service developments.
- 4** Value and promote all individuals and organisations that contribute to optimising self-management and build on existing good practice by identifying work in supported self-management that effectively meets people's needs.
- 5** All healthcare professionals should have access to skills-based training to support self-management and care planning, including group facilitation, active listening, goal setting and problem-solving skills.
- 6** All healthcare professionals should have ongoing education about diabetes and new developments.
- 7** Health services, working with partners, should train and support people with diabetes to influence and contribute to service improvement, redesign and monitoring, to advise on the self-management support services required.
- 8** Development of better levers, systems and incentives that encourage healthcare professionals and services to prioritise support for self-management, for example the inclusion of structured education as a quality and outcomes framework indicator as part of a care plan.
- 9** Independent accreditation and quality assurance of education and self-management programmes is needed to ensure that people with long-term conditions such as diabetes have access to high quality support programmes meeting general and condition specific needs.
- 10** More research into the provision of structured education for children, and looking at different ways to provide information and support to children and young people with diabetes is needed.
- 11** Better working with families and people with diabetes together as a team.
- 12** Monitoring of self-management support services and patient reported outcomes to value individuals' confidence and perceptions about self-management support and abilities.

Further information

Diabetes UK has published a booklet that outlines the standard of care that should be received from the NHS:

Diabetes Care and You – What Diabetes Care to Expect

Go to www.diabetes.org.uk/onlineshop or call 0800 585 088

Diabetes Education Network

www.diabetes-education.net



The charity for people with diabetes

Macleod House, 10 Parkway, London NW1 7AA

Telephone 020 7424 1000 **Fax** 020 7424 1001

Email info@diabetes.org.uk **Website** www.diabetes.org.uk

A charity registered in England and Wales (no. 215199)
and in Scotland (no. SC039136). © Diabetes UK 2009

November 2009