# Supporting patients learning to live with diabetes: a phenomenological study

Karin Johansson, Sofia Almerud Österberg, Janeth Leksell and Mia Berglund

raditionally, diabetes care has been provided from a diagnosis-centered perspective, but this has changed in recent times to more person-centered approach. A person-centred approach is also necessary when specialist nurses support patients learning to live with diabetes. This change has been described as a paradigm shift, which can be difficult to achieve because it requires training and a change in the nursing culture (Anderson and Funnell, 2010; Boström et al, 2014a). Studies have shown that patients with diabetes become more active and show greater satisfaction with the care when it is based on their individual needs (Boström et al, 2014a; Jutterström et al, 2016). Diabetesspecific training has become more common for nurses today. But this approach has not affected how group training for patients with diabetes is carried out and patient participation in setting treatment targets was found to be low in one Swedish study (Husdal et al, 2016).

A diagnosis of diabetes means there will be several changes to a person's life, requiring a process of adaptation as they learn to live with the illness (Andersson et al, 2008; Ingadottir and Halldorsdottir, 2008; Johansson et al, 2009; Kneck et al, 2011; Jutterström, 2013). For the present study, 'learning' is defined as the patient accepting the illness as a physical change, with a new understanding of themselves as a person with diabetes (Johansson et al, 2015). Learning is complex, with physical and emotional challenges (Whittemore and Dixon, 2008) and is lifelong (Kneck, 2015). Ingadottir and Halldorsdottir (2008) described the difficulty of learning to live with diabetes without letting it dominate one's life. Learning should, according to Berglund (2014) and Whittemore and Dixon (2008) be supported at an existential level, as it is partly about changing as a human being.

**Karin Johansson,** Diabetes Specialist Nurse in Primary Health Care, Department of Administration/Primary Care, Region Kronoberg County Council, Växjö, Sweden, karin.johansson@kronoberg.se

**Sofia Almerud Österberg**, Associate Professor, Department of Health and Care Sciences, Faculty of Health and Life Science, Linnaeus University, Växjö, Sweden

**Janeth Leksell,** Associate Professor, School of Health and Social Sciences, University Dalarna, Falun, and Department of Medical Sciences, Uppsala University, Uppsala, Sweden

**Mia Berglund**, Associate Professor, School of Health and Education, University of Skövde, Skövde, Sweden

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#### **ABSTRACT**

This article describes a study of the phenomenon of supporting patients who are learning to live with diabetes, from a diabetes specialist nurse (DSN) perspective. Guided by principles of reflective lifeworld research, data from six interviews (four in groups and two individual) with 16 DSNs were analysed. The results show that, in order to support learning, DSNs use a self-critical approach with the insight that they should not take over responsibility for their patients' diabetes. The DSNs support, encourage and challenge the patients to self-reflect and take responsibility based on patients' own goals and needs. To provide support, DSNs need to assume a tactful, critically challenging approach, dare to confront patients' fears and other emotions and have the insight to know that the responsibility for learning and integration of the condition lies with the patient. To be able to support patients in this way, it is necessary that the DSN is mentored and supported in this role.

**Key words:** Diabetes ■ Diabetes specialist nurse ■ Lifeworld ■ Phenomenology ■ Reflection ■ Patient support ■ Sweden

Diabetes specialist nurses (DSNs) have the responsibility to supply information and support to patients with diabetes, consistent with international, national and regional guidelines for diabetes care (Swedish Association for Diabetes Specialist Nurses, 2014; American Diabetes Association, 2016; National Board of Health and Welfare, 2017; International Diabetes Federation, 2018). But how do DSNs define 'support for learning' and do the DSNs feel that they are giving this support? A literature search did not find any earlier research into this specific aspect of diabetes care.

Support from a patient perspective is three-dimensional: individual, professional, and social (Johansson et al, 2016). Social support is defined by Hupcey (1998) as existential and physical, as well as experienced as complex because of the multiple parameters involved. Professional support is mediated by caregivers in their practice (Hupcey and Morse, 1997) and generally follows guidelines and policies. From the patients' perspective, support for learning could be understood as self-responsibility, openness about the illness, reflection supported by technology such as a blood glucose meter, and an open-minded approach (Johansson et al, 2016). According to Zoffmann et al (2008), the importance of communication and reflection is undervalued in clinical practice. They described communication and reflection at several levels from the general to the specific, with different possibilities for creating depth in the reflection. Berglund

Table 1. Characteristics of interviewees		
Interview	Number of diabetes specialist nurses	Care unit
1	2	Primary care (private) (specialist diabetes care)
2	6	Primary care
3	3	Specialist diabetes care
4	1	Specialist diabetes care
5	3	Primary care (private)
6	1	Primary care

(2014) developed a didactic model based on a lifeworld theory to support learning for patients with a lifelong illness, which includes giving patients support to talk about themselves as 'I' instead of 'one'. Nurses using this model to support learning should examine the patient's goals and needs, and clarify the patient's responsibilities (Andersson et al, 2015). Findings indicate the need for comprehensive changes, focusing on strategies that replace a disease-oriented approach with a combined disease-life approach (Zoffmann et al, 2008).

Earlier studies have described the phenomenon of learning to live with diabetes (Johansson et al, 2015) and learning from the patient's perspective (Johansson et al, 2016). Based on earlier study results and with the focus on patient learning, the authors identified a need to describe the DSNs' experience. The present study describes the phenomenon of support for learning to live with diabetes from a DSN perspective.

#### **Materials and methods**

This study explored and illuminated DSNs' approaches to the subject of supporting the learning of diabetes patients through the reflective lifeworld research approach, based on a phenomenological theory as described by Dahlberg et al (2008), which examines the study of the structures of lived experience. 'Lifeworld' refers to Husserl's idea to go 'to the things themselves' and describe phenomena as they are lived and experienced by individuals (Husserl, 1973).

#### Participants and data collection

Following the approach of Dahlberg et al (2008), interviews were used to explore the DSNs' experiences. DSNs were recruited from seven care units in South Sweden: three specialist diabetes clinics and four primary care units. Sixteen nurses working with a variety of patients with diabetes were recruited. The DSNs were provided with literature on previous studies focusing on patients' experiences of learning support in diabetes. Four interviews were conducted in group sessions and two in individual ones to get more variation and greater detail of the phenomenon under investigation (*Table 1*). Length of experience of working as a DSN varied from 1 to 30 years. They all met patients with both type 1 and type 2 diabetes, although the majority of patients attending the specialist clinics had type 1 diabetes, while most in the primary care units had type 2. The interviews were conducted in conversational form, beginning

with open questions about how the DSNs support patients learning to live with diabetes. Follow-up questions were asked to gain deeper insight into the phenomenon. Such questions included:

- Tell me more
- In what way?
- How did you experience it?
- Do you have some examples?

#### **Ethical considerations**

Approval for the study was granted by the Regional Ethics Committee of Linköping (reference number 2015/283-32). Field officers approved participation. Respondents were provided with oral and written information about the aim of the study before they provided written consent.

#### **Data analysis**

The analysis was carried out according to reflective lifeworld research principles (Dahlberg et al, 2008). Data were examined for meaning with an open and reflective attitude. The interviews were recorded and listened to and the transcripts read with the object of getting a sense of 'the whole' and becoming familiar with the text.

Questions were asked, such as:

- How do the data reflect the phenomenon (support for learning to live with diabetes)?
- What is the intrinsic meaning of the words?
- How can we understand the phenomenon in this way?

After that, the text was gradually divided into 'meaning units', smaller parts, containing meanings connected to the phenomenon (Dahlberg et al, 2008). The meaning units identified in the text were grouped into clusters, depending on their differences and similarities. These clusters highlighted patterns of meaning, and as a result an 'essence' emerged (Dahlberg and Dahlberg, 2003). The aim of the analysis was to describe the essence of the phenomenon and all its variations, called the constituents.

#### Results

#### Essence

To support patients learning to live with diabetes means the DSN must have a self-critical approach with the insight not to take over the patient's responsibility for their condition. The DSNs support, encourage and challenge the patients' understanding and actions. Support is given by conveying knowledge in a creative and tactful way, adapted to the individual patient. The DSNs try to support patient learning by starting reflection processes by asking questions with the purpose of clarifying the relationship between, for example, biomedical values and patient actions. The purpose of the support is that the patient should feel responsible for making conscious choices to reduce the risk of diabetic complications. Providing support aims to increase the patient's willingness and ability to take charge of their condition. Sometimes, the DSNs said they felt unable to make the patient understand or affect their willingness to change. Providing emotional and practical support created security by being there for the patient, emphasising the patient's ability, providing tools and instilling hope and courage.

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Four constituents of the phenomenon under study were identified:

- Realisation that the responsibility is the patient's own
- To meet and challenge the patient's understanding
- To meet and handle the resistance to change
- To be creative and provide tools.

#### Realisation that responsibility lies with the patient

To support patients learning to live with diabetes, the DSNs take on a reflecting, self-critical approach. At the first meeting with a newly diagnosed patient, the DSNs try to instil a learning and supporting approach. They try to give the patient a knowledge base that will help them feel secure enough to take responsibility for their condition. This responsibility is important, both from a medical perspective and for the patient's life situation. One DSN described it like this:

'When dealing with a patient who has recently been diagnosed with diabetes, I give information about the illness, and then I say that we will be seeing each other about 2 hours a year in the future. Apart from that, the patient will have the responsibility, so it's important to ask questions, to let me know if anything is unclear and to find out as much as possible. It is important to me to know what the patient would like to know, so I give the right information. I think it is important for the patient to realise that "I have to handle this myself" with our support.'

Questions for reflection such as 'What would you like to do?' and 'What can you do?' are used to support and motivate the patients to take responsibility. The purpose of these questions is to help their patients find their own solutions, and the DSNs also encourage patients to look for information on the subject themselves and try their own ideas. One DSN described the importance of being honest and daring to challenge, while at the same time being supportive in the following way:

'Sometimes, I feel we need to be a bit hard and be honest. We must not be afraid of that ... not hurt ... not offend, but tell them in a gentle way.'

The DSNs felt that patients who take charge of their diabetes increase their freedom, and they are able to affect the development of their illness and thereby their own future, which motivates the DSNs to maintain this approach. The following is a typical description of this, given by several DSNs in the study:

'If they want to, newly diagnosed patients with diabetes type 2 usually get the chance to change their lifestyle before other treatments are considered. If the blood glucose levels are improved, they are stimulated to make further changes, and they get positive feedback from the effect of their lifestyle change.'

The DSNs were aware of the differences between patients. Some make the expected changes to their lifestyle. Some do

not want to take charge but want to hand responsibility to the nurse. Others push their blood glucose levels too low, which is a challenge for the DSNs as this can be dangerous.

#### To meet and challenge the patient's understanding

In order to meet and challenge the patient's understanding, it is important to understand how the patient understands their situation and actions. A trusting relationship furthers the support. This is achieved by believing in the patient, and not neglecting their emotions or frightening them. It is about getting to know the patient as a person, how they learn and how they handle life changes, as well as what the individual patient feels are challenges and opportunities in this new situation. One DSN described it like this:

'To meet the patient at his/her level, as patients have different backgrounds and interest in the illness and have different levels of acceptance of the illness. I ask them what they feel is difficult and hard about the illness, and let them tell me about their feelings and what they find difficult.'

To be able to give support, it is important to get information about the patient's previous experiences, what they know about diabetes already, and explain the seriousness of the condition. One DSN described it like this:

'You want to make it less dramatic for those who have previous experience [of someone with] diabetes with blindness and amputations, but there is a danger if you make it too undramatic, as this could make the patient neglect it.'

The DSNs try to understand, and to make it clear to the patient, what it is that prevents them from making changes that are necessary for their health. Obstacles may involve fears and/or feelings of shame, which make it difficult to tell others about their illness. They may not want to be seen to be taking insulin because of embarrassment. Some patients may not dare to take insulin for fear that their blood glucose levels will be too low. The DSNs try to support patients in their learning and integration of the illness into their lives by being aware of the fears and suggesting that they make changes in small steps. This means creating security and a balance between the desire for good blood glucose control and the fear of too low blood glucose levels and unwanted complications. One DSN described it like this:

'The target level is important, and it may not be 5 but you select something between 7 and 10. Because I think many of our patients fear feeling unwell. Nearly all of them have experienced a somewhat dramatic event when they have lost their mind [had a hypoglycaemic episode] or whatever. It is fear that stops them from fighting to reach lower (blood glucose) levels.'

Being tactful about the patient's understanding of their illness could mean only giving information on request, to allow time for knowledge to sink in and changes to become new habits. Knowledge can be conveyed in creative and flexible ways, meaning that the DSNs try to relate to the patient's interest and encourage the patient to ask questions. By asking questions that create reflection, DSNs can make sure that the patient integrates new knowledge and understanding into their life habits. This requires patience.

#### To meet and handle resistance to change

To support patients in learning to live with diabetes means to handle and challenge the patient's resistance to change. The DSNs said it was difficult to deal with patients' excuses for not taking responsibility for their illness, even though the DSNs are aware that it is difficult to change behaviours. Most often, lack of knowledge is not the problem, but a lack of acceptance of their illness. One DSN described how she challenged this sort of behaviour:

'I had an interesting meeting with a patient I had been seeing for several years. She never wanted to change anything because she felt very well and thought everything was fine. It would not have been possible to get through to her even if her HbA1c level went up. We started talking as usual. But then I said to her: "Honestly, you have never wanted to understand this thing about diabetes." There was silence for a while, and then she said: "No, I haven't." After that, she has changed. She has started taking insulin, giving blood samples, checking what she eats and what her blood glucose levels are. So, something has happened.'

This challenging question that created reflection led to an honest discussion and gave the patient an understanding of her actions and that she could make different choices. This meeting is an example of situations where DSNs feel happy and proud.

DSNs said they sometimes feel they are not doing enough, that they are not properly equipped and that they lack support from other professionals to give the patient the right support. At larger clinics, the DSNs feel the security of having colleagues available for discussions, which was not available to those in smaller clinics. Sometimes, DSNs said they felt like a container into which the patient can dump their negative feelings.

The DSNs said it was difficult when patients do not come to terms with how serious their diabetes is, particularly if they suffer complications. The DSNs then examine their behaviour to see if they could do more, and they are aware that personality has a major impact on what changes the patient is willing to make. Pride comes when a patient reaches their target levels after a long time and a lot of hard work.

#### To be creative and provide tools

To the DSNs, supporting patients in learning to live with diabetes means finding suitable tools that support reflection, such as metaphors, images, summaries of blood glucose levels and group activities. To make these tools work requires a trusting and non-threatening relationship. Here, the DSN is 'supportive more than policing' and supports with a positive approach by

'finding the little things that are good' in the patient's situation. DSNs said it was important not to be judgemental but to make sure sessions with patients were positive and enjoyable.

The DSNs said it was important that they conveyed their belief that the patients could cope with their diabetes and were able to instil hope. This supporting relationship requires creativity, being sensitive to the patient's needs, focusing on the patient's understanding and any lack of knowledge. The patient is urged to ask questions and the DSNs would stress to patients that no questions are silly or unnecessary. The DSNs would support learning by being available for questions, reflection-creating dialogue and discussions. One example of reflection-creating process is the way in which the DSN uses a patient's diabetes profile with current levels and changes over time to encourage reflection and dialogue. One DSN described this approach as follows:

#### 'I hand over the diabetes profile to the patient, and then I ask what he/she thinks of the levels. Then we talk about them.'

Another DSN said she draws arrows, and happy and sad figures to clarify the relationship between the different parameters. The DSNs also supported learning by supplying patients with blood glucose meters and by conducting a reflection-creating dialogue on blood glucose levels. Through the dialogue, the DSN supports the development of the patient's understanding of how the body reacts to changes in diet, exercise, temperament and hormone fluctuations, infections and other illnesses. Other tools supporting learning include technology to continuously measure blood glucose levels and give instant feedback on how they are affected by activities. One DSN described it like this:

'I think they get to see aspects of diabetes that they never knew about. Ups and downs they did not see before, even when they made 7-8 measurements a day, become very clear.'

The DSNs support learning by being sensitive to obstacles and fears, which are valuable for individual adjustment to give the right tool at the right time to the right patient. One DSN said:

## 'To some patients, blood glucose measurements can be a nuisance, and they can feel just as healthy with an HbA1c measurement every three months.'

To others, insulin treatment can be scary, and some patients are afraid of the syringe, which requires that the DSNs are creative. DSNs said they let patients practise inserting the insulin pen into a ball before they use it on themselves. Others have a fear of hypoglycaemia and of losing control. In these cases, the DSNs provided technology that gives a warning of low and high blood glucose levels, which creates a sense of security. This helps the patient to dare to try to keep their blood glucose at lower levels or to be more active.

By inviting patients to group meetings, the DSN provides the opportunity to exchange experiences, which adds, develops and maintains active knowledge. One DSN told us about her experience of group activities: 'Those who were not so much involved in their diabetes felt that listening to other participants revived their knowledge, and they could understand it better than when we informed them.'

Learning is supported by the DSN asking the group reflection-creating questions, instead of lecturing. The DSNs felt that patient information leaflets were a good tool that supported learning. One drawback was that they were not available in all languages.

#### **Discussion**

This study aimed to describe DSNs' experiences of the phenomenon of supporting patients to learn to live with diabetes. The findings highlight that, in order to support patients, DSNs must use a reflecting, self-critical approach that includes the understanding that the patient is responsible for their own learning and that the role of the DSN is to encourage and challenge the patient to self-reflect and take responsibility based on their own goals and needs. To give support in this way requires that the DSNs do not adopt the medical paradigm of control and instead use their medical knowledge in reflection-creating questions based on a lifeworld perspective.

The results of this study highlight the importance the DSNs placed on taking an active and sensitive approach to providing information at the initial interview with patients newly diagnosed with diabetes. The DSNs' experience is that the patients' perception of the initial information on their diabetes will affect how the patients integrate their illness into their daily lives.

This experience is congruent with previous study results, which show that the first diagnosis of diabetes creates a chaos that becomes the foundation for how patients understand new knowledge, but that they rather quickly accept the illness and continue with their lives (Johansson et al, 2009). Berglund (2014) highlighted that initially these patients have a fear of changing to the conditions of the illness. Hörnsten et al (2011) described a turning point when the illness is integrated emotionally and existentially and self-management is seen as a normal daily routine. To support the integration, fears need to be challenged. In this study the DSNs were aware of and considered patients' fears, but they did not seem to focus on them, which demonstrates the need for nurse education that supports reflection and helps counteract patients' fears and feelings of guilt and shame.

The results also highlight that the DSNs saw that the responsibility for learning lies with the patient, which is congruent with patients' experiences in earlier studies (Jallinoja et al, 2007; Johansson et al, 2016) and is expressed as the patient's commitment to take charge themselves (Graffigna et al, 2014). The DSNs expressed feelings of powerlessness when patients are not prepared to make changes. The DSNs had to restrain the urge to take over and guide the patient towards set goals, but instead to find out what the patient is prepared to change (Pill et al, 1999) and not set the agenda for what the patient needs (Boström et al, 2014a). They should support the patient in taking on the role as the 'final problem solver' (Zoffmann and Kirkevold, 2007).

This approach requires DSNs to be creative in finding tools that facilitate reflection and support the patient in reaching an understanding of the requirements of the illness. Support for the patients' learning requires dialogue and didactics that create reflection, and several models have been created (Wikblad et al, 2004; Berglund, 2011; Zoffmann et al, 2016). One study showed that a didactic model, combined with mentoring, changed DSNs' approach to supporting patients with diabetes from simply providing information to helping the patient to make their own decisions and take responsibility for their health (Andersson et al, 2015). Jutterström et al (2012) demonstrated how focusing on emotional and existential aspects of having an illness created a turning point. The results of the present study supported these findings.

The results also show the importance of individual adjustment to meet patients 'where they are', as found in a previous study (Todres et al, 2014). With an understanding of the patient's personal perspective on the illness, focus is placed on the existential uncertainty that they are experiencing, rather than on symptoms of the illness. This is valuable for the integration of the illness into the patient's experience (Whittemore et al, 2008).

The results show the value the DSNs placed on making individual adjustments to information provided and carefully encouraging reflection because of an understanding of the person's needs. They might motivate a patient to start reflecting by asking value-clarifying questions or by pointing out possible inconsistencies in the patient's responses to the illness, an approach supported by Zoffmann et al (2008). Sometimes, the patient's understanding needs to be confronted (Andersson et al, 2015), and the patient encouraged to reflect on their situation, an approach that can be used without moralising to create interest and trust (Zoffmann et al, 2008). Sometimes the patient's understanding needs to be confronted with reflection aimed directly at the individual patient's actions to show the importance of taking responsibility. This was shown in the present study, where one DSN asked a patient a direct question about acceptance of their diabetes, which created reflection and motivation to change.

Encouraging reflection in this way is in line with the theory of how learning creates and supports reflection and motivation according to the lifeworld theory (Husserl, 1973; Gadamer, 1989; Merleau-Ponty, 1995) and the didactic model (Ekebergh, 2009).

In the study, the DSNs described the importance of involving the patients in group activities, which made them feel secure and motivated to reach their goals by taking more responsibility for themselves. Boström et al (2014b) explained how group interventions, where they could discuss things with each other, made patients more active in dealing with problems. Their discussions became richer as they received several perspectives, and they were in a forum in which they could discuss psychosocial and existential matters.

Some of the DSNs expressed feelings of inadequacy. Some felt they lacked mentoring support from colleagues and therefore felt unable to fully support patients with diabetes to take charge of their condition themselves. The need for mentoring was supported by Boström et al (2014a) who, together with (Huber et al, 2011), advocated support and

#### **KEY POINTS**

- In this study, the researchers interviewed diabetes specialist nurses (DSNs) with the aim of understanding how they support patients learning to live with diabetes
- The DSNs in this study took a self-critical approach with the insight to not take over their patients' responsibility for their diabetes
- The DSNs used creative ways to support patients' reflections, such as using metaphors, images, summaries of blood sugar levels and group activities
- The DSNs needed to be sensitive to patients' obstacles to selfmanagement of their diabetes. They aimed to give the right tool at the right time to the right patient
- Mentoring is necessary so that DSNs can carry out this learning and supporting role successfully

extensive training for DSNs. Group work has been shown to be helpful for DSNs by helping them confront and clarify their own professional role and reflect on their role in the patients' learning process (Andersson et al, 2015). To support the patients' learning, the DSNs require competence and the ability to see the patient's needs, obstacles and opportunities (Friberg et al, 2012). This requires pedagogical competence and a didactic model that supports learning, further training and mentoring (Friberg et al, 2007; Holmström and Röing, 2010; Scambler et al, 2012; Noor Abdulhadi et al, 2013; Boström, 2014a; Andersson, 2015; Jutterström et al, 2016).

#### Limitations of the study

Recruitment to the study was purposeful and aimed at sample variation. In the area where the study was conducted, there were no male DSNs, who might have given a different perspective. The combination of group and individual interviews meant the results varied. Individual interviews were richer in detail, while the group interviews encouraged more reflection.

Although the DSNs in the study had been given information on previous studies of patients' experiences of learning and support for learning, this subject often took a long time to come up in interviews. The DSNs could more readily describe work methods than define support for learning. Obstacles to developing understanding of this subject were feelings of inadequacy rather than a lack of time. DSNs tended not to reflect upon the support for learning they provided, but when questioned, realised that they did use this approach. One DSN said: 'When you ask, I think it is like this.'

To ensure trustworthiness of the results, the researchers sought to maintain an open attitude and regularly reflected on their pre-understanding (Husserl, 1973), and have strived to challenge any preconceived ideas (Dahlberg et al, 2008). The authors also strived to 'not make definite what is indefinite' to not draw conclusions that could not be fully supported (Dahlberg and Dahlberg, 2003). To increase trustworthiness of the results, all the researchers discussed the findings to reach a consensus.

#### **Conclusion and recommendations**

The DSNs interviewed for this study support patients to take charge of their diabetes by setting up joint goals to strive for. To provide this support, DSNs need to assume a tactful and critically challenging approach, dare to confront fears and other emotions, and accept the fact that the responsibility for learning about and integrating the illness into everyday life lies with the patient. The support is individually adjusted based on the patient's wishes and needs, as well as their ability to grasp information and make changes. Creative approaches are needed to find suitable ways to convey knowledge, remove obstacles and create reflection.

The authors suggest that group education and discussion would assist the DSNs by helping them to confront and clarify their own professional role and reflect on their role in the patient's learning process. To be able to give support in this way, the authors recommend that DSNs should receive mentoring and support in this learning and supporting role. **BJN** 

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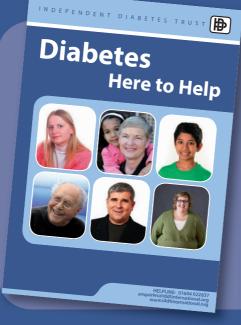
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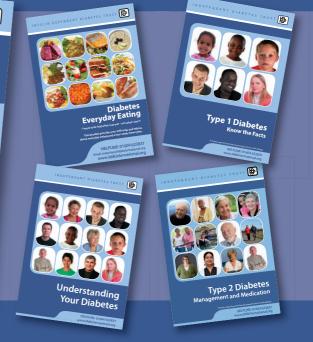
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#### **CPD** reflective questions

- Think about patients with diabetes in your area of nursing what do you do to help them learn about or manage their life with this condition?
- Consider how you could better support patient with diabetes in learning to live with their condition
- What support do you need in your work so that you can help patients learning to live with diabetes or any other chronic condition?
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