‘What sort of diabetes have I got?’
The importance of a label

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‘What’s in a name? That which we call a rose by any other name would smell as sweet.’ Romeo and Juliet (II,ii,1–2)

When an individual receives a diagnosis this precipitates a range of responses which are influenced by the meaning of the diagnosis, or label, to that person and those around them. Subsequent changes to the diagnosis, progression of the disease process, and changes in treatment regimen frequently trigger responses similar to those associated with the initial diagnosis. The labels type 1 diabetes, type 2, pre-diabetes and insulin-dependent diabetes each have a different meaning in the context of making a diagnosis pertaining to elevated blood glucose levels.

There are common themes associated with the reaction to diagnosis which include ‘why me?’ in the search for meaning, managing the unpredictability and uncertainty of fluctuating blood glucose levels, and managing uncertainties and inconsistencies resulting from different sources of information. A further challenge can be learning to deal with the response of others to the new label and to behaviours that interrupt the usual routine such as blood glucose monitoring, or treating an episode of hypoglycaemia.

Coping

Coping is the behavioural response influenced by thoughts and feelings, aimed at reducing distress and restoring the emotional equilibrium. This may be adaptive or maladaptive, for example making positive changes to lifestyle or avoiding insulin because of the thought ‘it makes you fat’. The coping strategies are dynamic and change over time in response to specific situations and circumstances.

When the diagnosis is modified – for example type 2 diabetes to type 1 – the impact on the patient is influenced not only by the meaning of the amended diagnosis but also by any change in treatment regimen. Likewise the transition from oral to injectable therapies, or multiple daily injections to an insulin pump, is accompanied by an emotional response to the change. For many people the change can feel as if they have been newly diagnosed all over again as the renewed attention to the condition and its treatment reactivates the initial thoughts and feelings. Opportunities to express feelings and manage the emotional reactions, and explore thoughts and beliefs about the condition are an essential aspect of coping.

‘They weren’t sure at first, they weren’t sure if I was Type 1 or Type 2. There’s no in-between thing like type 1.5, then they decided I was Type 1. It was confusing.’ (healthtalk.org.)

A diagnosis is made on the basis of a collection of symptoms. When it becomes possible to say ‘I am a person with diabetes’ rather than use ‘diabetic’ as an adjective, it becomes possible to step back from the emotional entanglement with the condition. This opens the potential to perceive the condition as manageable and controllable. However, if the meaning associated with the diagnosis results in an overwhelming emotional reaction this impedes rational information processing and maladaptive coping frequently results.

‘Diabetes is me, it’s moved in and taken over.’ (healthtalk.org.)

Living with the label

Health-related stigma is the negative social judgement based on a feature of a condition or its management that leads to perceived or experienced exclusion, rejection, blame, stereotyping and/or status loss.1–3

‘I’ve got this thing for the rest of my life.’ (healthtalk.org.)

In the first two studies of their kind, Browne and colleagues explored the evidence for diabetes-related stigma in type 1 and type 2 diabetes and concluded stigmatisation is part of the social experience of living with diabetes.3,4 Despite the aetiology and management demands of type 1 and type 2 being clearly different, stigma, blame, negative social judgements, exclusion and discrimination were consistent themes elicited from the participants. These themes are frequently associated with clinical depression, low self-esteem and low self-confidence.

‘I’m not a druggie, I’m just a diabetic.’5

The role of the media in perpetuating incorrect information and negative stereotypes was reported to be significant, together with family and friends giving rise to feelings of being judged and excluded. People living with type 1 diabetes reported experiencing the stigma of type 2 by association. Comments from health care professionals were also reported to give rise to feelings of blame and failure in both groups of patients.

‘…because every time they mention obesity, they mention diabetes, on the media, every single time. So obviously you interpret that everybody who is diabetic is fat…’ (healthtalk.org.)

Common strategies to deal with perceived stigma are avoidant self-protection manifested by an unwillingness to disclose the condition or an avoidance of health care appointments. This minimises distress by avoiding having to deal with the reactions or ignorance of others, and situations giving rise to feeling judged or blamed.

‘I call it the blame and shame disease.’4

Modifications to diagnosis or treatment

While there is no alternative to insulin in the treatment of type 1 diabetes, as technologies and insulins develop there is an element of choice available as to whether to take on the new developments to optimise outcomes
and quality of life. People new to insulin pump therapy, despite reporting positive outcomes in terms of glycemic control and general psychological aspects, may struggle with the renewed visibility of the condition.\textsuperscript{9} In contrast, when glycemic levels cannot be optimised using oral medication in type 2 diabetes it is necessary to transition to injectable therapies, insulin and/or a GLP-1 analogue. A number of studies report a delay in starting insulin which has come to be known as psychological insulin resistance (PIR) leading to persistently elevated blood glucose and an increased risk of complications. Over half (54.9\%) of those asked in the Diabetes Attitudes, Wishes and Needs study (DAWN) indicated they were worried about the possibility of insulin therapy and more than a quarter (27\%) randomised to insulin in the United Kingdom Prospective Diabetes Study (UKPDS) initially refused.\textsuperscript{8,12} This reluctance can arise for a variety of reasons, including a sense of failure in managing the condition and perceived stigma associated with injectable therapy.\textsuperscript{8–12}

**Pre-diabetes or borderline diabetes**

It is widely accepted that the number of people developing diabetes can be reduced by identifying those who are at risk, and making recommendations for lifestyle change. In recent years the term ‘pre-diabetes’ has been used following the identification of risk factors. There is some discussion in the literature about whether it is helpful to give this diagnosis when there is increased risk rather than an inevitability that the factors will develop into type 2 diabetes.\textsuperscript{13,14} A recent literature review explored the impact of this diagnosis on behaviour change and concluded that feelings of uncertainty about the disease, its management and physical consequences affect a person emotionally and socially.\textsuperscript{14} Lifestyle changes were seen as a struggle and were only undertaken if they did not impact on daily routines and habits.

**The importance of good communication**

The label or diagnosis is the path to getting the right sort of help which suggests that any modification or revision of the original diagnosis, such as type 1 to type 2 diagnosis, is likely to result in different treatment options. For some this takes the process of adaptation back to the shock and disbelief associated with the initial diagnosis.

As stated at the beginning of this article, when an individual receives a diagnosis this precipitates a range of responses which are influenced by the meaning to that person, and to those around them, of the diagnosis or label.

Meaning is derived from what is known about the condition, its treatment and wider implications. It is accepted that the experience of the patient in receiving a diagnosis, what it will mean together with treatment options and changes with time is crucial in terms of the way a person copes, adjusts and accepts the necessary changes to their life and those around them. When people are shocked and anxious this will impede their ability to process new information. The communication style is most important in the dialogue between the health care professional and the patient receiving a label. It is essential this is a collaborative process involving the patient at all stages and preparing the patient from the beginning, for the possibility of change and also for disease progression. This is particularly important for those newly diagnosed with type 2 diabetes where the outcomes range from potentially reversing the condition to injectable therapies. Making available an appropriate amount of time over a period of weeks is essential, whether individually or in groups, to present the necessary knowledge and information and reduce the likelihood of information overload and feelings of being overwhelmed at the point of diagnosis. People do not remember everything from a consultation, so it is important to repeat spoken information, support it with written information together with repeated checks that the meaning has been understood and the necessary knowledge and information learned. In a recent study looking at ways to improve the transition from oral to injectable therapies, the themes identified were the emotional response, communication, knowledge provision and support from health care practitioners.\textsuperscript{15}

**Practical tips for talking and listening**

Person-centred care is characterised by the relationship between the health care professional and the patient, working together to understand what is important to the person in the process of making decisions about their care and treatment. It is often more important to ensure people feel understood rather than attempt to ‘fix’ or reduce what is a ‘normal’ human response to an unexpected change.\textsuperscript{15}

Key things to think about are giving information, supporting, drawing out and coping with emotion. When there is a lot of new information to convey it is for the health care professional to make a decision about what is essential to keep the patient safe and what can appropriately be delivered at later opportunities. It goes without saying that what is offered initially must be accurate, while also conveying the expectation that things may change. Determine if there are any misunderstandings about the condition that can be corrected thereby reducing unnecessary anxiety. Be careful not to offer opinion as if it were information.

Draw out what the person is thinking and feeling by asking open questions. Open questions are ones that begin with ‘What’, ‘Why’, ‘When’ or ‘How’ and require more than a one-word answer. Allow plenty of time for the person to work out while they are talking what they are thinking, and don’t rush to fill the gaps. Learn to feel comfortable with periods of silence. Your questions are to help your patient process the meaning of their new situation. A brief example is given below:

**Closed question:** ‘Do you feel that now you have a diagnosis you have an explanation for your symptoms?’

‘Yes.’

**Open question:** ‘What was your first reaction to being told you have diabetes?’

‘I was relieved at first because I thought at least I know what was making me feel so tired… [pause]. Then
I started thinking ‘What have I done to deserve this?; I eat properly and exercise regularly, until I started feeling so ill at least. Now I don’t know what to think, there’s so much to take on board.’

Reflection: ‘It sounds as if you have been confused and angry but now you feel overwhelmed?’

‘My daughter is getting married later this year. We have decided the menus and everything. There has been so much to organise and now I have to get my head around this. I read in a magazine I should lose weight… well I really need to do that anyway but I already have my wedding outfit and…. oh, I just feel so sad, mixed up and confused.’

Validation: ‘It is to be expected you will have some confusing feelings at such a busy time for you… It may be helpful to talk a little more about the foods you like to eat and how they affect your blood sugars. Would you like to do that?’

At this point it may be appropriate to explore the concerns the patient has about food choice in the context of the wedding, and link that back to her usual routine, offering factual information where appropriate.

It is often the case that what is of particular concern for the individual appears to be unrelated to the diagnosis and may seem irrelevant in the context of a health consultation. Accept the concerns expressed and validate the emotional content; be careful not to sound dismissive or judgemental.

If it seems as if the conversation is grinding to a halt, reflect on what has been said so far and this will act as a prompt for more, thus continuing the conversation. For further examples when dealing with a new diagnosis and follow-up consultations see the work of Jen Nash.16,17

Summary
Labels or diagnoses serve a purpose to access appropriate care and treatment. They carry a meaning for the individual, giving rise to thoughts and feelings which influence coping behaviours. The impact of this can be mitigated by supportive listening, accurate information and emotional support.

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Declaration of interests
There no conflicts of interest declared.

References
5. Saarinen T, et al. Insulin pump therapy is perceived as liberating, but to many it can imply a sense the diabetes made visible. Eur Diabetes Nursing 2014;11:38–42.