

Long-term conditions

Type 1 Diabetes

Queen Alexandra Hospital, 12/04/2016

Four people, plus Emma Giles and Nick Brooks

Information:

A strong sense that even after decades with the condition there was always still more to learn. Support for structured education, and the opportunity for ongoing, regular contact. Positive feedback for Jigsaw course, also positive references to Daphne / Sailing education courses.

Criticism of occasions when a new diagnosis is made – “they say ‘here’s a leaflet’ and then you don’t see anyone for weeks”.

But, conversely, there is also a danger of ‘information overload’. A preference for ‘staggered’ information – focus on “the most important things” first, such as carb-counting, and then build up reserve of knowledge gradually after that. “If you gave people all the information at once, it would blow their mind”.

Some positive experiences: “I was lucky when I was diagnosed, the nurse was really good”, and “I had a pack from the Diabetes Specialist Nurse, and that was very useful”.

Peer support:

Linked to information, the importance of ‘signposting’ people to non-NHS support was highlighted.

Peer support offers the possibility of emotional support, and the NHS was described as offering nothing in this regard. Lack of emotional/psychological support was a very, very strong theme – all participants were clear that it was ‘totally lacking’, and extremely important.

“Hugely overlooked.... There is nothing”. “There is no weight given to the psychological aspects of living with the condition”. “I effectively had a breakdown, but there was no opportunity for counselling – the psychological burden is never addressed”. “It took me turning up to my dietician in tears before I could be referred for any support – the diabetes team could talk to me about my symptoms, but not the psychological impact of the conditions.”

“It is a life sentence. A life sentence of tests, of injections, being told you might never have children”.

Repeated references to “burnout”... the continual, and cumulative need to always be managing the impact of diabetes, which intrudes on all aspects of life, all the time – and the lack of recognition of people being in this state. “I became completely overwhelmed...”

But peer support was highly valued. "I had a 'buddy' assigned to me when I was diagnosed – we're still good friends now". "There are really good buddy systems in there – it so helpful, in terms of emotional support".

"Lay educators" were referred to positively, although with an acceptance of the limitations of this approach – specifically the difficulty in being able to offer clinical advice. "We know more than the GPs – I could teach someone more than a GP could, we are an underused resource".

"It is isolating – I felt incredibly lonely for years until I met other people with the same condition. You get emotional support, a sense of community – when you meet someone else with Type 1 you are instantly friends."

"Peer support is very, very important in terms of getting information – it's huge. It is essential to put people in touch with peer support groups." Agreement that peer support would have to be "type 1 specific".

Technology:

Generally positive about technology – excited by the prospect of being able to record data from pumps/monitors, and automatically download it, for access by either the patient or healthcare professionals.

Also saw technology as potentially enabling/supporting a change in the way care is provided: "If the knowledge and technology was there, I think that everything could be moved out of hospital".

One person recounted how she had a problem at 10pm and tweeted it to her consultant – she got a reply in no time! (Generally, patients are younger, and so appear to be more comfortable with social media / new communications).

Various apps were cited as helping with self-management – although a sense that there were so many out there that it was hard to know which one to use.

"If you are introducing new technology, you need specialist input to ensure you are using it effectively."

Generalists v specialists:

A very strong preference for specialist input – in fact a sense that only specialists could help.

"Some of the advice I have been given by my GP could have cost me my life."

"It's not a criticism of GPs, but in terms of long-term management I wouldn't look to them. If they can just recognise the symptoms, they've probably done their job."

Various references to advice received from GPs and practice nurses regarding the need for more/less insulin – advice which it was claimed later turned out to be wrong/potentially dangerous.

Several people reported that comments/advice from primary care staff could be actively disliked, not just of limited use. For example: “I don’t like going to my GP because they tell me I have to control my sugar, that I could go blind, that I could have a stroke – as if I don’t know that. It is demoralising”. Or: “GPs don’t understand the issues of daily management, and so can be patronising.”

Access was key – whether it was a ‘specialist phone line’, availability of specialist knowledge at night or over the weekend, or via social media. But this was coupled with a very strong sense that only *Type 1* diabetes specialists were appropriate. (One story of a patient who called 111, was transferred to a specialist, who sorted the right medication, and alerted the pharmacy that they were on their way – very, very positive experience!)

“In the hospital, even the receptionists know about your condition, and understand it.”

“In an ideal world you would have specialist nurses working in the community.”

“Ideally there would be a community setting offering everything you can get in a hospital, but in a more convenient location. There would be flexible appointments, opening evenings and weekends, and the chance to use Skype.”

Acute v Community:

There was a feeling that the ‘regular stuff’, such as blood/urine/foot/eye tests could be carried out in primary care, by primary care staff. But a strong preference for specialist expertise. “Primary care is a good place for the tests, but I wouldn’t look to them for advice”.

“I think that specialists can work in the community, I don’t have a problem with that. But... the danger is that if there is just one person, or a small team, spread across a range of community settings it might become very difficult to get appointments to suit you.”

“Retinal screening, foot checks... if you could get a whole series of checks done without having to go back to your GP, and without having to keep asking for yet more time off work, that would be great.”

Some willingness to travel to community services – “people would travel, if it meant accessing the right care”.

Self-management:

Technology was thought to be a ‘game changer’ – both in terms of glucose monitoring, etc, and also communications, such as Skype, email, social media.

NOTE: a few negative references to inpatient care – reports that staff took away insulin, etc as a matter of course, which people felt left them unable to self-manage/anxious/vulnerable.

“Pumps”

“Not everyone wants a pump, everyone is different. However, in other areas people are given a pump without having to go through a trial, or without being told all the time that their pump could be taken away.”

Overall – what would brilliant look like?

“Not having to do things twice”. Two of the participants reported needing to have blood tests taken twice, on a regular basis, because the GP systems couldn’t ‘talk’ to the hospital systems. (They lived in East Hampshire, and West Sussex, respectively) . Others also talked of the possibility of repeating tests/procedures – and this was seen as a potential frustration of moving services into community/primary settings.