Early onset type 2 diabetes: findings from a qualitative insight study

Purpose of the study

- A qualitative research project was commissioned by NHS England and Diabetes UK in February 2024 to gather insight from 30 people aged 18–39 years with early onset type 2 diabetes to explore their experiences, insights and feelings around diagnosis and their subsequent care.
- Sessions were conducted both in person and online. The sample included a mix of age, gender, ethnicity, and length of time since diagnosis.

Key findings

The research highlighted the lack of understanding of early onset type 2 diabetes (EOT2D) among the cohort and the importance of raising awareness of the complications associated with EOT2D amongst the public, patients and health care professionals.

Experiences of diagnosis

- Few people reported early warning signs and having non-diabetic hyperglycaemia / pre-diabetes prior to diagnosis.
- Care and advice provided at diagnosis had an impact on an individual’s ability to manage and whether they felt alone or supported.
- Many described feeling guilt and denial that they have been diagnosed at a young age.
- Some people were unsurprised and had expected to develop type 2 diabetes due to their family history.
- However, others described alarm, shock and lack of acceptance.
- Most reported little discussion about the prospect of remission.
- People said they had less contact and follow up with their clinical teams than they would have liked.
- If additional services were offered at diagnosis, most accessed these.

Experiences of care and self-management

- Experiences of good care involved empathetic conversations, with clear information and follow up. There was signposting / referral to other services and agreed treatment plans with next steps.
- However, for some participants, it felt like medication was the ‘go to’ for managing diabetes, with many not informed of the support for self-care available online through Healthy Living (healthyliving.nhs.uk) or offered referral to the NHS Type 2 Diabetes Path to Remission Programme.
- Referrals to other programmes for weight management (not always diabetes-specific) and exercise classes were variable.
- Some people felt they were left to struggle on their own.
- Support at the early stages of diagnosis, tailored to those aged under 40 years, was highly valued by study participants.

Pregnancy and pre-conception planning

- For those in the sample who were planning pregnancy, all had diabetes-related complications and were struggling to conceive.
- Many felt caught in a cycle of trying to reduce blood sugar levels enough for pregnancy, resulting in challenges in sustaining motivation and mood.
- Most were previously unaware of the risks of adverse pregnancy outcomes if blood sugars remained high.
- Awareness of pre-conception support was very low across the sample.
- Most stated that once pregnant they received good care (felt well looked after with access to support and regular follow ups).

Additional challenges for different groups

- For those with learning difficulties, things felt overwhelming, complex and frightening, especially at diagnosis, this increases the chances of avoidance behaviours, and makes their management harder.
- For those from minority ethnic groups, recurrent themes were the associated social and cultural issues around ‘traditional’ food that would be high in fat, sugar and carbohydrates and issues with adapting meals.
- Younger members of the sample (18-25 years) were more motivated to explore remission possibilities and welcomed input from any relevant services. They felt stigmatised with the negative associations of having EOT2D and some admitted to hiding the diagnosis.

Suggested interventions from study participants

- Practical ‘bite size’ information at diagnosis.
- Support with self-care and management other than just medication.
- Development of individualised 3-month plan at diagnosis with goal setting – and to then be followed-up.
- One-to-one holistic advice and encouragement, taking lifestyle into consideration.
- Access to emotional/psychological support.
- Availability of a diabetes ‘navigator’ healthcare professional for contact in the weeks/months after diagnosis to support through the adjustment phase.
- Dietary advice and tips that include culturally-specific types of food (e.g. simple switch out tips for ghee/oil/rice/bread).
- Opportunities for regular check-in appointments.
- Signposting to age-relevant peer groups to share ideas and ‘buddy’ systems to provide support and encourage accountability.

“My GP was really kind and helpful when they gave me the diagnosis, they explained to me what is going on with my body and the process of care and appointments I would need to attend and why. They were really supportive.”

Please note: The views listed above are from study participants and do not represent the views of NHS England or Diabetes UK. This guide was produced by the National Diabetes Programme Team. If you require any further information, please contact us via the team mailbox at: england.diabetestreatment@nhs.net