

Adjusting to your child's Type 1 Diabetes Diagnosis

A diagnosis of Type 1 Diabetes can be overwhelming for both the patient and caregiver, fraught with many emotions:

- Shock (“a week ago life was normal, how can this be happening?”)
- Fear/worry (“how will I/they ever have a normal life?”)
- Anger (“why did this happen to me/my child? It’s not fair”)
- Sadness/grief (“the life I thought I/my child would have is gone”)
- Guilt (“did I do something that caused this?”)
- Denial (“it’s probably a misdiagnosis”)

How can Social Work help?

Hospital Social Workers work with children and their families to help them cope with their illness and adjust to their outside world. We can guide you through the stages of acceptance and provide emotional support where needed. We aim to ameliorate the factors that are hindering your emotional wellbeing such as family conflict, grief and loss and trauma. We address protective concerns and can immobilise community services and supports if required.

Some typical responses your child may have to their diagnosis may include:

- Feeling isolated from their peers or feeling embarrassed about sharing the diagnosis with others.
- Behaving as though they don't have diabetes; avoiding testing or injecting insulin
- Feeling sad or angry
- Behavioural changes (for younger children this could be ‘acting out’ or ‘regressing’. For adolescents, opening up about their feelings).
- Feeling guilty that they have ‘caused’ or are to blame for their diagnosis.
- Fear and worry about the immediate and long term health issues that may accompany diabetes - some children may become scared to go to sleep for fear of overnight hypos)

These feelings are normal; adjustment takes time. These feelings may wax and wane over time, but generally reduce in intensity the further away from diagnosis you are. Whilst your child may never feel happy about having diabetes, over time, you and your family will adjust to living a life that includes diabetes. Allowing space for your child to express their feelings is important. It allows them to move towards accepting the diagnosis.

How you can help your child adapt to their diagnosis at home:

- Encourage them to take age-appropriate roles in managing their diabetes (e.g. wiping their injection site with an alcohol wipe, priming the needle, choosing the injection site). Encouraging your child to have some independence over their health helps them to have a sense of competency and confidence.

Information for patients, families and carers

- Try not be over-protective and limiting of their freedom– encourage the same independence from your child with diabetes as your child without– lowering the expectations of your child will send the message that they are not as capable as others.
- Support their strengths and interests that are not related to their diabetes – your child is more than their diagnosis.
- Encourage openness and model being comfortable with discussing diabetes. This sends the message to kids that they can also be open about their health and talk without shame or embarrassment.
- Encourage or facilitate your child to meet other kids living with diabetes – meeting peers with diabetes can minimise feelings of isolation and also provide kids with a safe space to share their honest feelings about their diagnosis. See our support section below for more information.

Application Process for Carers Allowance:

Type 1 Diabetes entitles you to Carer's Allowance. Carer's Allowance is a fortnightly supplement through Centrelink with a linked health care card. Your social work team will provide you with a step-by-step guide in how to apply at diagnosis. Please Note: there are residency requirements and income testing to apply.

Supports:

- **Diabetes Victoria Camps** for children aged 4 -17 years of age. For more information please email camp@diabetesvic.org.au or visit <http://www.diabetesvic.org.au/how-we-help>
- **Diabetes Victoria's Type 1 Peer Support Groups**. These groups are subject to change so please visit <http://www.diabetesvic.org.au/peer-support-groups> for more information.
- **JDRF Peer Support Program** is a volunteer network that connects people affected by Type 1 Diabetes. Please visit <http://jdrf.org.au/peer-support-program/> or contact peersupport@jdrf.org.au
- **Royal Children's Hospital Chronic Illness Peer Support (CHIPS) Program** offers a range of peer group experiences for young people aged 12-25 years of age. For more information please visit <http://www.rch.org.au/chips>.

In the same way that we cannot pour from an empty cup, it is difficult to support others emotionally if we are feeling overwhelmed. Seek support through family and friends, your child's diabetes team or the wider diabetes community if you feel that you are not coping.



Department of Paediatric Endocrinology and Diabetes (DPED)
(03) 8572 3051