

EMOTIONAL ADJUSTMENT TO DIABETES

6.1 THE ROLE OF THE DIABETES SOCIAL WORKER

The diabetes social workers are members of our multidisciplinary team, and are available to support children, young people and families in dealing with the impact of diabetes on their lives. The support is available while the child is a patient, from diagnosis through to when a young person transitions to adult services.

Social workers provide a range of support and assistance that may be needed when a child is admitted into hospital or as an outpatient.

This includes:

- Counselling
- Supporting families through times of crisis and distress
- Providing education and information
- Advocacy
- Planning for discharge from hospital
- Referral to community agencies and support services
- Delivering group work programs
- Providing information about community resources, accessing practical and material assistance

6.2 INITIAL DIAGNOSIS

When your child is diagnosed with type 1 diabetes it **affects the whole family**. A period of adjustment is required. During this time, your usual ways of coping with things are disturbed and you are likely to feel vulnerable and confused. There are significant feelings of loss and grief around the diagnosis and this takes time to process.

You may experience a whole range of feelings including:

- Shock
- Denial
- Anger
- Sadness or depression
- Fear
- Guilt



6.3 ADJUSTING TO DIABETES AS A PARENT

It is important to keep in mind that this difficult time will pass and you will regain your feeling of balance. It is helpful to recognise that you are in a vulnerable state and need to be mindful of your own needs.

Tips for helping your child include:

- Go back to normal routines
- Be patient with your child
- Help your child understand what is happening
- Allow your child to talk about their feelings and worries
- Set normal limits
- Encourage your child to spend time with friends
- Help your child to do some things on their own



A new diagnosis of diabetes may create difficult emotional issues for young people. Children look to their parents for support about how to manage their own emotions. This can be challenging for parents as they may also be struggling with their own feelings. It is important that parents and/or caregivers get support from family members, friends, support groups, GP's or other professionals, and the diabetes team.

Each child and adolescent is an individual and may experience different emotional responses at different times including:

- Difficulty coping with the emotional reaction of family members
- Feeling anxious about having diabetes
- Fear of needles and injections
- Frustration over the daily tasks of managing diabetes
- Feeling embarrassed about their diabetes
- Fearful of "being different"
- Worrying about school

6.4 FAMILY RELATIONSHIPS

A crisis puts stress on a family and close relationships. You may find yourself being irritable. **Remember that you are all under stress and these reactions are normal.**

Sometimes partners or other family members feel "out of step" with their reactions to the diagnosis. One parent may be tearful and want to talk about things — the other becomes practical and wants to "get on with it". **These are different ways of coping with the same situation.**



Accepting each other's differences can help people to support each other.

6.5 BROTHERS AND SISTERS

Siblings of the child with diabetes also need to have their feelings understood. They need to know what is going on and be given a simple explanation about diabetes. Some may fear that they too will get diabetes. Some siblings may react to the extra attention given to the child with diabetes. They also need support and reassurance.

6.6 FEELING CONFIDENT WEARING DIABETES TECHNOLOGY

Social work can offer information and advice to support parents to manage the change with technology through their children/teenagers journey. It is important that you feel open to talk about any issues.

What can your Social Work Team offer:

Discuss ways to help your child and teenager feel confident wearing T1D technology

Primary and high school children may feel different to their peers because they are wearing diabetes technology, so it is important to encourage confidence. A good exercise to do with your child/teen is to role play ways they can respond when faced with common questions they may be asked:

Do injections hurt? Is Diabetes contagious? Will it go away? Can you eat chocolate? Should you be eating that? Why do you wear that on your arm? Are you allergic to sugar? Can I have a go with your pump? Did you get diabetes from eating too many lollies?

6.7 SAFE USE OF MOBILE DEVICES WITH TYPE 1 DIABETES

Setting up healthy routines

The advancement of technology to assist the daily routine of diabetes is extremely helpful. However, it is important to create clear boundaries in the use of technology. We strongly suggest all children and teenagers have a routine at home, during the school week – around wake up time, meals, and bedtime. These routines are important to keep on weekends and school holidays as well to assist with good emotional and physical energy. Within their routine there will be fun activities, exercise, and most likely screentime.

Parents' Guide to Screen Time Daily Hours

Parents role is to support children and teenagers to achieve a healthy mix of screen time with other activities.

Children and teenagers are easily influenced by parents' habits. If you are being responsible with your mobile devices, they are more likely to be as well.

Australian Federal Government screen time standards are:

- no screen time for children younger than 2 years
- no more than one hour per day for children aged 2–5 years.
- no more than two hours of sedentary recreational screen time per day for children and young people aged 5–17 years (not including schoolwork).



Creating a “tech agreement”

A “tech agreement” creates a set of clear rules and expectations around your child/teen's online behaviour. The purpose of a tech agreement is to open discussions about the time your child/teen spends online. “Tech agreements” add a sense of formality regarding the child/teen's access to the internet and digital devices and reiterates the consistent and positive behaviour expectations. Keep in mind that your children/teenagers may be strongly influenced by their peers.

- 4-8yr**
No access to social media. Children's TV and child suitable games are appropriate. (0–2-hour limit)
- 9-11yr**
Setting clear rules and boundaries for this age is important. Ensure your child is fully aware of the expectations regarding their online behaviour and the consequences should rules be broken e.g. No screen time on the day the rule is broken, return the following day to usual routine and reward positive behaviour (2-hour Limit)
- 12-14yr**
It is important parents stay firm at this age with “tech agreements” – ‘tweens’ within this age group are easily swayed by their emotions and lack critical thinking to make appropriate decisions consistently. “Tech agreements” need to be firm but fair, reward positive behaviour. (2-hour limit on top of screen time homework)
- 15yr plus**
Open and honest conversations about expectations in the online world. Focus on the attitudes and behaviours expected from them. It is important that the parents also role model appropriate online behaviour. e.g., Family meals are device free, make sure you as an adult respect this rule. (2-hour limit on top of screen time homework)

Technology Agreement example:

OUR TECH AGREEMENT	
School and Weeknights	2 hours per day 5pm-7am: devices used only for diabetes management
Weekends	3 hours per day
Holidays	3 hours per day
Attitude	Do my best to share with my parents what I am doing online

Everyday Rules

I know how to get help if I need to block or report people
I won't try to access content I know is not meant for me
Only share or post anything I would not be prepared for my parents, grandparents, friends, teacher and my PCH doctor to see (because they might see it!)
At night in my room, I will keep my device where I can't easily get distracted. 'Remember to keep your phone in a box, draw or outside the bedroom door'. NOTE: A phone may need to be within 6 metres distance for Bluetooth to work for diabetes technology.
If I make poor choices this may include losing my privileges for short period of time

Examples of safe screen time apps:

Apple:

- (external website) [Apple Family Sharing](#)

Android:

- (external website) [Digital Wellbeing for Android](#)

Other Time limit applications:

- [Bark parental control](#) (external website)
- [Qustodio parental control](#) (external website)
- [Beacon app](#) (external website)

Know your children/teenagers' social media apps

Supporting your child/teen's digital journey is important. With the increasing online world and the addition of technology with T1D, it is essential we are doing all we can to guide this journey. It is important to know what Social Media apps your child /teen may be using- they have an age rating ranging from 4 years to 18 years.

Common Apps are, but not limited to:

- **Social Media** – TikTok, Instagram, snapchat, BeReal, Facebook, Discord
- **Gaming** - Minecraft, Roblox, among us, Call of Duty, Coin Master, Pokémon Go & Pokémon Unite, subway surfers, wordscapes, 8 ball pool, candy crush, fishdom, Fortnite, clash of clans & Clash Royale
- **Shopping** – Amazon, Etsy, gumtree, temu, eBay
- **Entertainment** – YouTube, Spotify music, Netflix.
- **Education** – Google Earth, ChatGPT
- **Messaging** – Messenger, WhatsApp, Snapchat

Ask your child/teenager what they are using and try to initiate open conversations about their use.

Want more information?

<https://www.education.wa.edu.au/cyber-safety>

<https://www.ysafe.com.au/aboutus.html>

<https://www.esafekids.com.au/>

<https://www.esafety.gov.au/>

compiled by Kirsty Browne-Cooper September 2023

6.6 RESOURCES AND COMMUNITY SUPPORT



centrelink

Centrelink

Carer Allowance and Health Care Card (caring for a child under 16 years)

Type 1 diabetes in children under 16 years old is a recognised condition for Carer Allowance.

If you share the caring role with someone who is not your partner, you may both be eligible for some Carer Allowance.

Payment rate

Carer allowance comes with a Health Care Card (HCC). Having a HCC will give you concessions on health care costs. This means you can get cheaper prescription medicines through the Pharmaceutical Benefits Scheme (PBS). Other concessions are also available.

If you are receiving a Carer Allowance payment, each year, the following supplementary payments are currently also paid annually:

- ▶ Child Disability Assistance payment
- ▶ Carer Supplement for each child in your care who qualifies for Carer Allowance

You do not have to pay tax on Carer Allowance.

What happens when my child turns 16?

Centrelink reviews all payments when your child turns 16 and carer's allowance ceases at this point. You will, however, be eligible to apply for a "Health Care Card for former recipient of Carers Allowance Health Care Card", which can be applied for online or by submitting a paper claim form.

For further information, contact Centrelink:



visiting a local office



13 27 17



www.humanservices.gov.au

If you need assistance, please contact your diabetes team social worker on 6456 0413

Chronic Disease Management Plans

Children with a chronic medical condition and complex care needs such as type 1 diabetes are eligible to access a **maximum of 5 allied health services per calendar year with a Medicare Rebate**. Your GP will prepare a Chronic Disease Management Plan to facilitate referral to the relevant allied health services, which can include:

- ▶ Exercise physiologist
- ▶ Physiotherapist
- ▶ Psychologist
- ▶ Occupational therapist
- ▶ Podiatrist
- ▶ Speech Pathologist

Please speak to your GP or your Diabetes Team for further information.

Mental Health Management Plan

Adjustment to a chronic condition can be challenging. A mental health management plan is available through your GP. Your doctor can arrange referral to psychological support services in your area, with Medicare rebate for up to 10 appointments.

Please speak to your GP for further information.

Private Health Cover

Insulin pump therapy is provided by Private Health Insurance Companies. You will need to contact your private health insurer to check the level of cover.

Refer to the Australian Government website for information on the new tiers of hospital cover.

 <https://beta.health.gov.au/resources/publications/private-health-insurance-reforms-gold-silver-bronze-basic-product-tiers-fact-sheet>

There is generally a waiting period of 12 months.

Please contact the Diabetes team about loan of pumps during the waiting period. Donated pumps may be available for those unable to afford Private Health Insurance. Please discuss this with your Diabetes Team.



Ambulance Cover

All parents are encouraged to consider urgent ambulance cover for their child with type 1 diabetes. Ambulance services can be expensive and are not covered by Medicare.

Most major health insurance companies offer urgent ambulance cover.



MedicAlert Bracelet

All children diagnosed with type 1 diabetes are strongly encouraged to wear a MedicAlert bracelet. The cost of a MedicAlert bracelet starts at \$49 annually. Your diabetes nurse educator can assist in completing the form or you can access it online at:

 www.medicalert.org.au/

Pharmacies also carry Mediband bracelets. Information can be found on the Mediband website:

 www.mediband.com/au

Patient Assisted Travel Scheme

The **Patient Assisted Travel Scheme (PATS)** provides permanent country residents with financial assistance when travelling more than 100km to access the nearest eligible medical specialist service (including Telehealth).

PATS provides a subsidy to eligible patients, however it does not cover all costs associated with travel and accommodation. For more information about PATS visit:

 www.wacountry.health.wa.gov.au/pats or

 contact your local hospital or regional PATS office



National Diabetes Services Scheme (NDSS)

The **NDSS** is an initiative from the Australian Government which provides subsidised prices on a range of approved diabetes consumables, such as needle tips and blood glucose strips.

To be eligible to register you must:

-  Live in Australia
-  Hold a Medicare card
-  Have a diagnosis of type 1 diabetes

Registration is free. You will be provided with a registration form at diagnosis to complete which can be signed by your diabetes educator or doctor.

 www.ndss.com.au



Diabetes WA

Diabetes WA is a not-for-profit organisation which aims to provide training and support to school staff, NDSS product information, education programs and links to support groups. You can access monthly updates on research, programs, products and services. For more information, visit:

 www.diabeteswa.com.au



Juvenile Diabetes Research Foundation (JDRF)

JDRF is the leading global organisation funding type 1 diabetes (T1D) research. JDRF also support the type 1 diabetes community with information, resources, personal connection, and hope for the future. JDRF provide a peer support program which offers one-on-one support from an experienced volunteer who has lived with type 1 diabetes and can share practical advice. JDRF donates 'kidsacs' to PCH. They also administer a government funded pump program. For more information, visit:

 www.jdrf.org.au



Type 1 Diabetes Family Centre

The **Type 1 Diabetes Family Centre** provides peer and psychosocial support to children, young adults and adults with type 1 and their families. The service offers a range of events, including camps, speakers, workshops and community forums.



11 Limosa Close, Stirling WA 6021



(08) 9446 6446



www.typE1FAMILYCENTRE.org.au

Kids and Teens Diabetes Online

For kids and teens there are some great interactive websites on diabetes. Here are a few to start with:



Children with diabetes, from Kindergarten to Year 12, need to be safely supported with their diabetes management at school.

Students should be able to fully participate in school and by having better support for their diabetes at school, they will be able to reach their full potential.

Individualised Diabetes Management plans will be provided by your Diabetes Team to ensure that schools are equipped for your child's return to school. These plans are a day to day management plan designed as an agreement between parents, school personnel and clinical staff to ensure your child is well supported. The plan is reviewed on a regular basis.

Diabetes in Schools Program

Is the only nationally recognised training program for type 1 diabetes. There are three levels of training available:

Level 1 - Introductory Training, designed for all school staff (online)

Level 2 - Intermediate Training, designed for school staff who will be directly involved in supporting the student with type 1 diabetes (online)

Level 3 - Individualised Skills Training, designed for designated school staff, focuses on the individual's management plan (usually face to face)

Training can be organised by the school principal via:

<https://www.diabetesinschools.com.au/> or by contacting **NDSS Helpline: 1800 637 700**

Liaison teachers are based at PCH. Their role is to:

- Assist the parent and student in the transition back to school after diagnosis.
- Assist the parent and student with transition to kindergarten, pre-primary, a new school, high school or alternative programs.
- Provide resources for schools.