

Diabetes - Social Worker

Information for parents, patients and families – Type 1 Diabetes

This handout provides information for parents who have a child newly diagnosed with type 1 diabetes. Further information can be obtained by contacting either the Social Work Department (6456 2222) or the Diabetes Department at Perth Children's Hospital (6456 1111).

Diabetes Social Worker

Diabetes Social Workers are members of the treatment team and help families adjust to living with diabetes. When a child has type 1 diabetes, it is normal for both parents and the child to experience episodes of distress and difficulty. The Social Workers understand these feelings and events and can provide assistance.

The Social Workers also provide support in periods of transition including initial diagnosis, going from hospital back home, starting primary school, moving from primary to high school. The Social workers help parents and adolescents negotiate changes that lead towards the child self-managing their diabetes and independence. Social Workers can provide you with information about community resources and will advocate for you when required.

Your Diabetes Social Worker is:

Feelings at diagnosis

The period just after you discover your child has diabetes is likely to be a very unsettled time for the whole family. At this difficult time your usual ways of coping with things are disturbed and you are likely to feel vulnerable and confused. You may experience a whole range of feelings.

These include:

Shock: You may feel numbness and that you are operating on 'automatic' and that the news hasn't hit you yet.

Denial: The news feels so overwhelming that you simply can't believe it. You think that there has been a mistake. Children can also be in denial and can express this by trying to avoid injections or finger pricks.



Anger: You wish there was someone to blame. You may find yourself being angry with the doctors, nurses, your partner or other family members. You may ask 'why me, why my child?' People sometimes question their faith or feel that life has dealt them an unfair blow.

Sadness or depression: There will always be the feeling of loss associated with the loss of perfect health in a child. With any loss, grieving occurs and can continue on and off for some time. Your mood can range from feeling sad to feeling quite depressed.

Fear: You may be full of fears for your child including fear about the constant management of diabetes and the impact on their future. As you learn about diabetes and put your new skills into practice, these fears begin to fade.

Guilt: As a parent your instinct is to protect your child from hurt and harm. You may find yourself thinking about the last few weeks and wondering if you could have done something differently. There is nothing you could have done to prevent your child from getting diabetes. Sometimes brothers and sisters may have feelings of guilt. Children can feel guilty too. Sometimes they feel like diabetes is a punishment for something they have done wrong. We know from child developmental milestones that children are egocentric; therefore, they think that the world revolves around them. If something bad happens they tend to blame themselves. Constant reassurance that they are not to blame can help and talking to their social worker can also help them to explore these thoughts.

Adjusting to Diabetes

Keep in mind that this difficult time will pass and you will regain your feeling of balance. The feelings of shock and confusion will subside. Talking through your feelings with family, friends and members of the Diabetes team will be very helpful. Your social worker is specially trained to help you understand your reactions and make sense of your family's experience. Even if you feel that you are coping, their input will assist and support you in many other ways.

It is helpful to recognise that you as a parent are in a vulnerable state and so be mindful of your own needs. This can mean setting aside some time just for you. You may be feeling overwhelmed by the amount of information you have to learn and understand. Don't be afraid to ask the nurse educators or doctors to repeat or go over anything you don't understand.

The responsibility for day-to-day diabetes care ideally needs to be shared with a partner or another person close to you. This may mean giving basic education about diabetes management to a range of people.

Children's feelings

You are the best person to help your child through this difficult time. Your child may experience any or all the feelings described above. Like you, they need someone to talk to who is calm and can provide reassurance and support.

Be patient with your child

Children's reactions can include crying, temper tantrums, whining, clinging and acting out in frustration. Don't be alarmed if your child starts acting like a much younger child. Be patient and supportive. Your child is adjusting to big changes. These feelings and behaviours are common, but temporary and will stop in time.

Your child may be:

- Easily upset or angry
- Feeling anxious or confused
- Irritable or uncooperative
- Uncertain about what might happen next
- Fearful about what others will think
- Fearful of 'being different' to their peers
- Fearful of dying

Help your child understand what is happening

Use simple words that your child can understand. If your child is anxious about injections or finger pricks, explain the purpose is to help him or her feel better. Provide reassurance.

Family relationships

A crisis puts stress on family and close relationships. You may find yourself being irritable and flaring up easily. Remember that you are all under stress and these reactions are part of the situation. Sometimes partners or other family members feel 'out of step' with their reactions to the diagnosis. One parent maybe tearful and wants to talk about things; the other becomes practical and wants to 'get on with it' and not dwell on the sadness or other feelings. These are different ways of coping with the same situation. Accepting each other's differences can help people to support each other.

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 an appropriate explanation about diabetes and the daily care required. Some siblings may become very upset about what has happened to their brother or sister and may become fearful that they too will get diabetes or some other illness. Some siblings may react to the extra attention provided to the child with diabetes. Siblings require understanding, support and reassurance.

Adjusting to Diabetes after discharge from hospital

Go back to everyday routines

Normal routines help children feel safe. Help your child return to doing their usual activities as soon as possible. Diabetes loves routine.



“Feelings are much like waves, we can't stop them from coming but we can choose which ones to surf”

Be patient and give everyone time to readjust

Keep in mind that people in the same family can react in different ways. Brothers and sisters can feel upset too. Most family members just need time and reassurance that things are returning to normal.

Set normal limits

You may be tempted to relax the rules to help your child feel special, or to compensate for the hard times that they are experiencing. However, it is often better for your child if you set normal limits on behaviour and keep most of the family rules and expectations the same.

Allow your child to talk about feelings and worries

Ask your child (and brothers and sisters) what they are thinking, feeling and imagining. Be a good listener – and share the facts as well as your own feelings and reactions. Children may feel different from their friends and feel their life is ruled by diabetes and routines. They may be reluctant to let people know they have diabetes or be embarrassed to test blood glucose or eat when needed. They may become more dependent on their parents at a time when they would otherwise be becoming more independent.

Encourage your child to spend time with friends

After the diagnosis some children feel a little 'different'. They may also wonder how their friends will react. Invite your child's friends to visit. It may be helpful to assist your child in answering questions their friends or classmates may have about diabetes (Is it contagious? Why do you have to prick your finger? What is diabetes? etc.). Diabetes Camps, kids and teens on line and pen friends through JDRF can also be useful in reducing your child's sense of isolation.

Help your child do some things on their own

It is often tempting to do more for your child after they have been diagnosed with diabetes. Encourage your child to do the things (including jobs around the house) they used to do.

Find ways to communicate with your child about the diabetes

It is important that a young person's identity does not become defined by diabetes. It can be tempting to ask your child what their blood glucose levels are as soon as they walk through the door after school. Children do not want to identify themselves as a 'diabetic' with nothing else to offer or share. Try asking about other things first, for example how their day went. This will build your relationship and encourage communication. Adolescents have reported that the only thing they talk or argue about with their parents is diabetes. It is beneficial to develop an approach where diabetes management is regarded as important but can mostly be in the background while you get on with life.

**Encourage, help,
communicate**



After the initial learning phase

The “novelty” of the new routine wears off quickly and often young people hit a difficult patch some weeks after the diagnosis as they realise that diabetes is a permanent condition with continuing daily demands. Parents need to provide close support to their children and be prepared to take over control of diabetes routines again if needed for a time.

Take time to deal with your own feelings

It will be more challenging for you to help your child if you are feeling worried, upset or overwhelmed. Parents’ concerns include fear of low blood glucose levels and dealing with the day-to-day management issues associated with diabetes (diet, carbs, insulin, blood glucose levels, exercise, school, sleep). Parents are concerned about long-term complications. Parents also worry about how much responsibility they should let their child have for diabetes management and when to start handing over more responsibility for the child to self-manage. Most parents feel very protective about their child and worry when their child is away from them. Most people have very little understanding of type 1 diabetes or the level of time and commitment involved in living with diabetes. There is an enormous amount of time and effort required to explain the condition to family, friends, teacher and others.

It is important for parents and caregivers to get support from family members, friends, support groups or their General Practitioner if necessary. Take time to address your own feelings. At the regular follow-up clinic appointments, your social worker and other members of the diabetes team are available to help and advise you.

Follow up with Clinic Appointments

Even if you feel you and your child are adjusting and coping well with the diabetes management it is important to attend your scheduled clinic visits. As well as the physical check-up, there is help available for children and families who may be feeling overwhelmed with emotional impact of diabetes on their lives. Your Social Worker or a member of your diabetes team will be able to help you to consider what’s best for you and your family.

Resources and Community Support

Centrelink

Carer Allowance (caring for a child under 16 yrs.)

Type 1 diabetes in children under 16 years is a recognised condition for Carer Allowance. The Carer Allowance is a supplementary payment that may be available if you are a parent or carer who provides additional care and attention on a daily basis for a child aged under 16 years with a medical condition or a disability. You do not need to meet income or assets test to receive Carer Allowance. You do not pay tax on Carer Allowance

All carers of children with type 1 diabetes up to the age of 16 are encouraged to apply for Carer Allowance (Child).

Type 1 Diabetes in children under 16 is a recognised condition for carer allowance



Health Care Card

If you receive Carer Allowance you will receive a Health Care Card. Having a Health Care Card will give you concessions on health-care costs. This means you can get cheaper prescription medicines through the Pharmaceutical Benefit Scheme (PBS) and medical services funded by the Australian Government. Other concessions are also available.

If you are receiving a Carer Allowance (caring for a child under 16 years) payment on 1st July each year, you can also receive Child Disability Assistance and a Carer Supplement.

Parents/carers of children with type 1 diabetes can contact Centrelink on 132 717 or visit a Centrelink office where you will be asked questions to determine your individual circumstances and be issued the appropriate claim forms. You will be issued with a Health Care card once your claim has been processed.

What happens when my child turns 16?

Carers of young people with Diabetes aged 16 and over can apply to Centrelink for a Former Recipient of a Health Care Card. This allows young people who are still at school or studying, to continue to have a Health Care Card. For those parents receiving Carer Allowance, Centrelink should contact you when your child is about to turn 16 to review.

To find out more, contact Centrelink on 132 717, or visit your local Centrelink office or the Centrelink website, www.humanservices.gov.au/individuals/services/centrelink/carers-allowance.

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 and waiting periods. Please contact the Diabetes team for information about the loan of pumps during the waiting period.

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. If you currently have private health cover, check with your insurance provider that Ambulance Cover is included in your current policy.

For those parents who do not have Private Health Cover please consider taking out Urgent Ambulance Cover for your child. Most major health insurance companies offer Urgent Ambulance cover.

Patient Assistance Travel Service (PATS)

The patient Assisted Travel Scheme (PATS) provides financial assistance for permanent country residents who must travel more than 100kms to access specialist services. Contact the PATS clerk at your local hospital prior to departure for assistance with organising travel and accommodation.

There is also help available to country families who have arrived at Perth Children's Hospital in an emergency, through the PATS.

PATS can assist with your transport home and with accommodation in Perth if needed.

What you need to do

- Ask your Ward Clerk to have the PATS Appendix 4 form completed and signed by your doctor.
- Your ward clerk will then send the form to your Regional PATS office at your local hospital.
- When you know your child's discharge date, speak to the Ward Clerk and they will contact your Regional PATS office to arrange your transport home.
- If you are flying, you will need shoes and I.D.
- If you have driven to PCH, make sure you keep your receipts. You can claim a fuel subsidy from PATS when you get home.
- If you need somewhere to stay during or after your admission, contact your Regional PATS Clerk who will organise your accommodation in Perth. Ronald McDonald House can be a convenient option. Ask your PATS clerk to make the booking.
- An accommodation list is also available from the ward clerk. Keep your receipts if you arrange your own accommodation and claim your subsidy from PATS at your local hospital when you get home.

There is help available to country families who arrive at PCH for an emergency through the Patent Assisted Travel Scheme (PATS).



Chronic Disease Management Plans

Children with a chronic medical condition and complex care needs are eligible to access a maximum of five allied health services each calendar year with a Medicare rebate. Your GP will prepare a Chronic Disease Management Plan. Your GP would then refer you to the relevant Allied Health Services.

Eligible allied health services are:

- Dietitian
- Exercise Physiologist
- Occupational Therapist
- Physiotherapist
- Podiatrist
- Psychologist
- Speech Pathologist

A written report is provided by the therapists to the GP including assessments, treatment provided and future management. To find out if you are eligible to access therapy services through a Chronic Disease Management Plan please speak to your GP.

Mental Health Management Plan

A mental health management plan is available through your GP. Your GP can arrange referral to allied psychological support services in your area, with a Medicare rebate for up to ten appointments. Please speak to your GP for further information.

Medic Alert Bracelet

All children diagnosed with type 1 diabetes are strongly encouraged to wear a Medic Alert bracelet or necklet. The diabetes team can provide you with application forms and information.

Pharmacies and internet websites also carry Mediband bracelets. Information can be found on the Mediband website, www.mediband.com.au.

Child Dental Benefits Schedule

The Child Dental Benefits Schedule provides financial support for basic dental services for children 2-17 years. To be eligible you must be:

- Aged 2 to 17 years
- The family receives Family Tax Benefit Part A or Parenting Payment and are
- Eligible for Medicare.

Please discuss with your Dentist or call Medicare on 123011.

National Diabetes Services Scheme (NDSS)

The NDSS is an initiative from the Australian Government which provides subsidised prices for a range of approved diabetes products such as syringes, pens, ketone blood glucose test strips and urine ketone test strips.

To be eligible to register you must live in Australia and hold a Medicare card. Registration is free, and you need to complete a NDSS registration form. Your diabetes educator will give you this in PCH. The form needs to be signed by a doctor or diabetes nurse educator.

Website: 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:

Website: www.diabeteswa.com

Tel: 1300 001 880

NDSS registration forms are also available on the Diabetes WA website, www.diabeteswa.com.au or call 100 136 588.



Juvenile Diabetes Research Foundation (JDRF)

JDRF is an organisation dedicated to changing the future for people with type 1 diabetes by funding and managing type 1 diabetes research.

JDRF also provides support to the type 1 diabetes community with information, resources, activities and groups. An example is the JDRF Peer Support Program which connects people who are affected by type 1 diabetes and provides the opportunity to talk to an experienced volunteer who has lived with type 1 diabetes and can share practical advice.

Website: www.jdrf.org.au

Tel: 6444 0700

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 diabetes and their families. The service offers a range of events, camps, speakers, workshops and community forums designed to connect and inform people with diabetes. The Centre is in Stirling near the Osborne Park Hospital. Further information is available on the website.

www.type1familycentre.org.au

Tel: 9446 6446

There are some wonderful interactive websites for children and teenagers;

- www.as1diabetes.com.au
- www.diabeteskidsandteens.com.au
- www.jdrfkidsonline.jdrf.org
- www.diabetescounselling.com.au
- www.sweet.org.au, and
- Diabetes personal calculator (App)



For further information
please contact your
Diabetes Team Social Worker
at Perth Children's Hospital

Schools

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

Parents must agree and sign off with the school principal or delegate an Agreed Diabetes Management and Action Plan.

These plans are available on the Diabetes WA Website.

www.diabeteswa.com

Liaison teachers are based at PCH and their role is help and support children with type 1 diabetes and their parents at school, and to provide resources and training to schools.



Government of **Western Australia**
Child and Adolescent Health Service

This document can be made available in alternative formats on request for a person with a disability.

Child and Adolescent Health Service

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