



Insulin Dependent Diabetes Trust

For Family Carers

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IDDT is a charity concerned with listening to the needs of people who live with diabetes, understanding those needs and doing its utmost to offer help and support. We not only help those who actually have diabetes, but also their family carers – the husbands, wives, partners and parents. We all live with diabetes and we recognise that when one member of the family has diabetes, it affects all the other family members to a greater or lesser extent. Family carers have views and needs, they may well be different from those of the person with diabetes, but they are, nevertheless, valid and important.

Parents of children with diabetes are very special sorts of carers and if you are a parent then you should see our leaflet specially for parents and also our Parents' Supplement to the Newsletter, August 2000.

Facts about carers in general

- As long ago as 1990 the UK National Household Survey showed that 15% of the adult population are carers – this represents 8.5million people. 25% of carers care for 20 hours or more per week, 1 in 5 care for two or more people and 18% of carers are themselves over the age of 65. If the national agencies and statutory bodies had to provide paid workers for these jobs it would run into several billion pounds.
- Carers are the people that voluntarily look after the needs of a family member. They are firmly committed to the tasks they do and these can vary from almost any job to simply watching and listening possibly most of the day and night.
- Research by the Carers Association in Wales has shown that most carers report that their own health suffers as a result of their caring responsibilities.

The Carers Recognition and Services Act - UK

This Act came into effect in the UK in April 1996 and it has provided new rights for carers. The main aim of the Act is to make sure that Social Services listen to the carer and offer the help the carer needs. Previously only the needs of the person who was being cared for were recognised and NOT the needs of the carer.

Definition of a carer:

You are a carer if you are caring for someone with an illness or a disability regardless of whether that person is young or old, a relative, partner or friend. The person you are caring for does not have to live with you, they could live some distance away.

The role of Social Services:

Social Services and the local councils are there to help and support both you and the person you care for. Social Services firstly have to

assess anyone who needs care and provide services that help them to live at home. They may provide services directly such as a home help or they may purchase the services from voluntary organisations.

Carers' Assessment:

The Carers Act gives you, the carer, the right to ask Social Services for an individual assessment of the care you provide and your ability and willingness to go providing that care. If at any time the needs of the person you care for change, then you have the right to ask for a reassessment. But remember that before your needs can be assessed the person you care for must be assessed. While the Carers Act entitles you, the carer, to your own assessment, the services are actually provided to the person who is being cared for – this in turn offers you some support and help.

How to ask for an assessment

- Contact Social Services to ask for an assessment of you and the person you care for.
- Ask your GP or community nurse to contact Social Services on your behalf.
- The address of Social Services is in your local telephone directory but if you have any difficulties then contact the Citizens Advice Bureau.

Be prepared for your assessment

Think about the things that would help you and what are the most important aspects to you. Here is a suggested list to help you start:

- Changes to the home and any equipment that might help you
- Someone to help with personal care eg bathing
- A meal delivered to the person you care for
- A few hours break occasionally or a few weeks break on a regular basis
- Counselling or just someone to talk to.

Costs:

- There is no charge for the assessment
- As the services are provided to the person you care for, part of that assessment will involve their finances. Your financial position as the carer, should not be discussed.
- Costs of services may vary from area to area.
- Social Services should only charge people what they can reasonably afford – nobody should be caused hardship or refused access to services because they cannot afford to pay for them.

The role of caring can be very stressful and tiring and it is important that you seek help before you get to the state where you are so exhausted you can't even make the effort to look for the help you need.

Carers and Diabetes

We are well aware that for some people the effects of living with diabetes do not seem to put a strain on relationships but we are also aware that for others it does, either sometimes or all the time. Just as diabetes is different in everyone, so is the day to day living with it and we all have different ways of coping with it. Many people with diabetes would not consider themselves in need of a 'carer' and see themselves as totally independent, but that may not be how their partner sees the situation.

Quote from a carer: *“Independence is fine, but who picks up the pieces when they have a bad hypo? Who wakes up in the morning with only a bad headache, knowing nothing about the 3.00am battle with food – certainly not me!”*

Partners can feel:

- Excluded from their partner's diabetes even though this exclusion

may be quite unintentional on the part of the partner with diabetes and they may be unaware of how their partner feels.

- That their knowledge of diabetes is very limited because they have not been included in any of the education sessions at the diabetes clinic.
- They may feel frightened both on a day to day basis and for the future health of their partner.
- They may feel alone with their worries and fears with no one to talk to about their own feelings. Talking to an outsider can make them feel guilty and disloyal to their partner.
- They may feel angry. Diabetes has altered everything and the life they expected may no longer seem possible – this in turn can lead to feelings of guilt and selfishness.
- They cannot talk to their partner about their concerns because they do not want to upset them.
- They may feel that diabetes and the welfare of their partner is a huge responsibility for them and feel unable to cope with this responsibility that has suddenly been thrust upon them.

We also have to remember that carers are carers for life and they get older just like everyone else. Unfortunately people with diabetes may also get the complications and so the partner can be placed in the role of caring for 24 hours a day with little or no help and support. This can be stressful and tiring!

Research quotes:

The impact of severe hypoglycaemic episodes in patients with IDDM on spouses psycho-social status and marital relationships.
Diab Care 1997; 20: 1543-1546

This study found that spouses of people with frequent severe hypos had more fear of hypos, more marital conflict about diabetes management and more sleep disturbance worrying about night hypos than did spouses whose partners with diabetes had not had recent severe hypoglycaemia.

Spouse's worries concerning diabetic partner's possible

hypoglycaemia.

Diab Med 1998; 619-622

This study interviewed spouses of people who were treated in emergency for severe hypoglycaemia and the results showed the following:

- When the partner is late home, for nearly 20% of their spouses their first concern was the possibility of a severe hypo.
- Severe hypoglycaemia was a source of concern for nearly 66% of the spouses.
- For nearly 10% of the spouses the possibility of severe hypoglycaemia was 'always' a burden.

Tips for Carers, from Carers

From Margaret whose husband and son were diagnosed within 6 months of each other: *“My husband’s reaction to a hypo was to blame me for not giving him enough carbohydrate at the last meal and at the beginning I would get very upset at the things he would say. As time went on I realised that he was only saying them because he was hypo and I learned not to feel hurt and to ignore the things he said. This reduced the stress I often felt. My son’s hypos were very different and frightening because while he was using ‘human’ insulin he had virtually no warnings and I would have to lace cups of tea with sugar at 10 minute intervals during the night until he slowly came round. I learned that making sure that I had some time to myself helped me to cope with the stress of living with diabetes and I’m sure that my outside interests helped me.”*

From a Mum looking back over the years of living with diabetes in her daughter: *“Looking back I realise that I felt split in so many different directions. I cared for my son, I cared for my daughter with diabetes and I cared for their father but sometimes my daughter’s needs had*

to override those of her brother and father. For this I felt guilty. I’m sure that sometimes I ran around in circles trying to make them all equal – an impossible task because they are not all equal and they had varying needs at different times. Life became a lot easier when I realised that I should stop trying to be superwoman and to just do the best that I could for all of them.”

Beth from Kent amusingly describes how she learnt to deal with Ian’s night hypos while he was using ‘human’ insulin: *“We came to the conclusion that a blood sugar level of less than 9mmols/l before bed was rather too low and would almost certainly lead to a night hypo. I evolved my own way of restoring my husband to his senses. We have a plastic feeding cup with a spout and I fill it with orange squash with glucose dissolved in it. He drinks it easily and instinctively when I put it to his lips, while holding his head up with my free hand. I wait about 10 minutes and if he doesn’t reward me with a weedy smile, I repeat the dose. Happily he has only ever been slightly hypo since his change back to pork insulin and even at 2mmols can still take action himself.”*

Jan, a carer tells us: *“ My husband is not physically violent when hypo but he is verbally abusive and says some very hurtful things. I learnt to cope with this by regularly reminding myself that it was not really him talking but his diabetes. In other words, I learnt to blame diabetes and not him. It helps me to not feel so hurt and resentful.”*

A Message for Health Professionals

For a long time IDDT has put forward the view that carers should be more involved in their partner’s diabetes from either the beginning of the relationship, where there is pre-existing diabetes, or from diagnosis. Yet so often they feel out in the cold especially as far as healthcare professionals are concerned. Carers are the ones who pick up the pieces, who deal with the bad hypos and who smooth

over difficult family situations. But some carers tell us that they are not even allowed in the consulting rooms with their partners! If the partner with diabetes does not want them there, then this is a matter between the two of them, but if both partners want to be involved then there should be no question of 'not being allowed' into the consulting room. Carers are not 'interfering busybodies', diabetes does not just belong to the person with it but it belongs to the whole family.

Advantages of carer involvement

- The carer can have a valuable input to the visit. Is the doctor really getting a true picture of what's going on between hospital visits, how many hypos there have really been, how many violent hypos, and perhaps most importantly, how many hypos without warning symptoms? The person without diabetes certainly cannot report on these because he/she doesn't know they are having them! Involvement of carers in the clinic visits is not just a one way process of information being imparted to the carer.
- Any changes in the health or wellbeing of the person with diabetes are often noticed first by the carer.
- A well-informed carer can save in health costs by being able to deal with some of the problems that can occur at home and preventing hospital admissions.
- If healthcare professionals met the carers they would have a greater understanding of the whole family which would enable them to better tailor treatment regimes to individual needs.
- Carer involvement leads to the carers having more information and support which increases their self-confidence and removes some of the fears and feelings of exclusion.
- A more contented carer may well lead to a happier, less stressful home life and that has to be better for everyone. It can even improve the health of the partner with diabetes because stress affects blood glucose control.

Quote from Helen, who has diabetes: *"I have now changed my insulin from 'human' to pork and feel much better. My family says that I am back to my old self again. But I am angry that they had no opportunity*

to talk to my doctor about the changes that they had noticed so that the problems could have been sorted out sooner."

Research quote:

Unreliability of reports of hypoglycaemia by diabetic patients.
BMJ vol. 310, 18 Feb 1995

In this study 123 out of 155 patients reported that they had no severe hypos in the past 4 years but 16 partners had observed a severe attack in the previous year and 4 reported that severe attacks had occurred over 4 times a year. Of the 152 patients who answered questions on hypo awareness, 21 reported partial unawareness, 24 complete unawareness and the remaining 107 normal awareness. But of this 107, 20 partners disagreed – 5 stating that their partners were totally unaware and 15 that they were only partially aware.

Carers and Hypoglycaemia

Certainly from the contacts IDDT has had with carers, the greatest problems occur as a result of hypos, the fear of them, the handling of them, the responsibility for dealing with them correctly or being unable to cope with their partner's behaviour while hypo. We have no magical answers to these problems but it is necessary to acknowledge the difficulties that some carers do experience.

Embarrassment

It is well recognised that the people with diabetes hate the embarrassment that hypos can cause but carers can also suffer from embarrassing hypos too.

Quote from a carer: *"I remember going to a function at my son's school and half way through my husband, who had virtually lost his warning symptoms of hypos, started to behave in a silly fashion, as if he was drunk. I knew he was hypo and had to rescue the situation. But much*

embarrassment was caused for my son, even though I went to the school and explained. Do not let anyone believe that diabetes does not affect the whole family.”

Violence and Abuse

One fairly common difficulty expressed to IDDT by carers is the violent, aggressive or abusive behaviour of their partner when they are hypo. Many of these carers are women - maybe they feel unable to be physically in control because of the greater size and strength of their partner although it could simply be that women are more ready to talk about this issue than men.

We recognise that a lot of people never have hypos of this type and so it is difficult to understand what it is like to live with the fears that violent and/or abusive hypos produce for the carers who have to deal with them. It is understandable that frustration is added to the fears because no one understands how the carer feels. Family, friends and the health professionals at the diabetic clinic probably never see their partner in a hypo and so he/she appears OK and very ‘normal’.

Quote from a carer in just this position. She visited her GP to ask for help. His comment was *“Oh, he seems a very nice gentle soul.”* Undoubtedly true when he was not hypo. This lack of belief for the carer’s plight is insulting and just adds to the problems.

Despair

This is another emotion that is expressed to us. Not only do these carers have to deal with the violent, aggressive or abusive hypo, but they have to live with the fear of the next one. If the hypos are usually nocturnal, then going to bed each night is accompanied by fear and poor sleep. The ongoing nature of these hypos does lead some partners to feelings of despair and the relationship suffers accordingly.

Quote from a carer: *“Sometimes I just want to run away and never come back, but I don’t and I can’t.”*

Do we have any advice?

- Take action! Doing nothing can make a difficult situation worse, can increase tension and affect your own health.
- If possible, talk to your partner about what happens when they are hypo and about your fears.
- Discuss their diabetic control and if it is possible to avoid hypos by raising the blood sugars a little.
- Ask if you can attend the clinic with your partner so that you can both get advice.
- If your partner is unwilling for you to attend the clinic with him/her, then make an appointment for yourself to see the diabetes specialist nurse. Start here and express your feelings.
- Try to meet other carers in similar positions – the nurse may be able to help you with this. Talking to someone who understands can be a great help.
- If you feel you can no longer handle the hypos, call the GP or 999 and ask for an ambulance with paramedics aboard. [If this keeps happening somebody will at least take notice of your problems!]

Note: IDDT has a leaflet on hypoglycaemia that may be useful.



Respite Care

This is something we all hope will not be necessary for any of us but we have to be realistic – we all get older and people with diabetes can get complications and the care they need increases. This can be tiring and stressful for the carer.

What is respite care?

It is a break for the carer. It can either be for a few hours a week just to get out of the house and have time to yourself or it may be necessary to have a couple of week’s break from caring. Whichever is the case, the break can only be a rest if you know that your partner is being well

cared for by people who have sufficient knowledge of diabetes.

Is respite care available and how do I find it?

The first step is to actually admit to yourself that you need a break. This is not always easy because it can feel as if you are not coping. You can feel guilty because you are not doing all the caring. But it is important to remember that a break, even for a few hours a week, may well enable you to be a greater help to your partner because you feel better.

Respite care is not easy to obtain because if there is a shortage of funds within Social Services then it is often respite care that is cut back. Equally, suitable residential care is not easy to find because of the needs of people with diabetes. As we all know it is not just a matter of providing a 'diabetic diet'!

Quote from a carer: "I look after my 90 year old uncle who has diabetes and from time to time I need a break to recharge my batteries. He can be difficult, especially when hypo. My last experience of residential care has made it difficult for me to leave him where I feel he is properly cared for. One morning he was not given his morning injection because he was being violent. The carers in the home would not go near him and did not call a doctor. Needless to say he was having what was for him, a typical hypo and they didn't give him his breakfast either!"

To find out about the availability of respite care in your area contact

- Social Services
- Your GP or practice nurse
- Voluntary organisations such as the Carers Association, Age Concern, Cross Roads.

Remember that your break will only be one if you can leave the person you care for with people you are happy with, so do not accept something that is not satisfactory. Check that they know about diabetic care. If you spend your free time worrying about the care your partner is getting, then your break will be wasted.

IDDT is here to help – just call us. We understand and we all live with diabetes.

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