

# MENTAL HEALTH AND DIABETES

*Perspectives from people living with  
diabetes, their families and carers*



## EUROPEAN MENTAL HEALTH WEEK



**International  
Diabetes  
Federation**  
Europe



# EUROPEAN MENTAL HEALTH WEEK



Some 61 million people live with diabetes in Europe. Despite the advent of new medicines, tools and technologies which have revolutionised diabetes management and care over recent years, the condition continues to represent a heavy burden for people living with the condition and their families.


Diabetes management is hard, relentless and all-consuming. People living with Diabetes (PwD) and their relatives/carers need to take care of their diabetes seven days a week, 24 hours a day. This round-the-clock self-management is required to keep glycaemia (blood glucose levels) within target levels, thereby lowering the risk of developing life-altering diabetes-related complications in the medium to long-term. People living with type 1 diabetes (T1D) and those with type 2 diabetes (T2D) on insulin therapy must check their blood glucose levels throughout the day and adapt their treatment accordingly. Going for a walk or a jog, eating an ice-cream or drinking a hot chocolate, breast-feeding a baby – all need to be taken into account when managing diabetes.


People with T2D who are not treated with insulin also need to manage their blood glucose levels effectively throughout the days and weeks by adapting their diets – for example, seeking to eat in moderation foods which trigger fast/large hikes in blood sugar, generally following an appropriate medication strategy and increasing physical activity, which help lower blood glucose levels.


Despite this strenuous management, many PwD do not meet their health outcome targets and many develop diabetes-related complications such as cardiovascular diseases and diabetes retinopathy, which affect one third of PwD; and end-stage renal disease, of which 80% is caused by diabetes, hypertension, or a combination of both. Less visible and front-of-mind, but no less damaging, are mental health-related complications.

Besides the mental stress of those potential long-term complications, the every-day routine of treating a life-long condition for a minimum of 20-30 and potentially, up to 80+ years, can become overwhelming.

 **1/3** of PwD develop CVDs

 Diabetes/+ hypertension cause **80%** of end-stage renal disease

 **1/3** of PwD develop diabetic retinopathy

 PwD are **2 to 3** times more likely to experience depression than people without diabetes

Diabetes distress and burnout (whereby one feels completely overwhelmed by diabetes), depression, anxiety and eating disorders are all very common, and do not only affect people's quality of life and relationships but can also have an impact on their ability and willingness to self-care. Added to which, the fear of hypoglycaemia is also a very prevalent concern for many PwD.

This is why we call on healthcare systems not only to provide solutions to manage diabetes as a physical condition, but also to ensure that PwD and their carers/relatives receive the adequate and timely mental, emotional and psychological support they require at the time of diagnosis and throughout their life course. Peer-to-peer support is also vitally important. Online support networks have developed rapidly over recent years, and healthcare professionals (HCPs) also need to be aware of them and recommend them to PwD in their care.

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***On the occasion of European Mental Health Week, we have asked PwD as well as carers/relatives how they have been affected by a diabetes diagnosis; their perspectives are presented in this booklet.***

# DIABETES AND ITS IMPACT ON MENTAL HEALTH



## PERSPECTIVES FROM PEOPLE LIVING WITH DIABETES



### JOÃO, LIVING FOR 42 YEARS WITH T1D, PORTUGAL

*Living with diabetes always has an impact on mental health, even when people don't realise it. There are always times when diabetes gets in the way and makes it difficult to achieve what you want. In my case, on many occasions, diabetes was the cause of a minor depression and some crying. For instance, when I was not able to get good diabetes control no matter what I did to change the treatment, or in the old days when it was mandatory to eat every 2-3 hours, which created a difference between myself and my friends.*

### ERIK, LIVING FOR 24 YEARS WITH T2D, THE NETHERLANDS

*Sometimes living with type 2 diabetes is difficult or frustrating, but for me in general, I accepted my condition and deal with it.*

### ROSSITZA, LIVING FOR 28 YEARS WITH T1D, BULGARIA

*Living with a chronic condition like type 1 diabetes is an additional 24/7 job from which you never get a break - this can be overwhelming sometimes.*

*When I look back, living with diabetes impacted my mental health mostly in my school years. Nowadays, with all these new technologies, diabetes has become more and more visible and there is a lot of information about it. Back then, I was using a glucometer and insulin pens, which made it easy to hide it and keep it a secret - of course, this made things more complicated and heavier for my mental wellbeing. During your teen years, you just want to be a part of a group and not be different so I guess that is why I tended to hide my condition back then. Nowadays, I think that the situation has improved - kids have a lot more information on the topic - diabetes recently started to be represented in pop culture as well.*

### OLIWIA, LIVING FOR 6 YEARS WITH INSULIN RESISTANCE, POLAND

*The biggest challenge is fighting stigma and discrimination. Even though we live in the 21st century, people still believe in stereotypes. When you want to live your life, hearing people saying things to you such as: "it's your fault", "you deserve it", "you're lazy", "don't ask for help when you put it on yourself", "will I get infected by you?" does not help with taking care of your mental health.*

### LUCIJA, LIVING FOR 19 YEARS WITH T1D, CROATIA

*Puberty is hard on its own. If you live with diabetes, it's even harder. Most kids who discover they live with diabetes in that period of their life struggle.*

### VALERIE, LIVING FOR 6 YEARS WITH T2D, IRELAND

*I know that younger people living with diabetes can find the work environment a challenge. Some of them hide their diabetes for fear of seeming different or of being misunderstood.*

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## PERSPECTIVES FROM PwD'S FAMILIES



### **DRAŽENA, MOTHER OF MARIN, LIVING FOR 5 MONTHS WITH T1D, CROATIA**

*The fear, the unknown and the unexpected, together with the limited quantity and variety of food and the extra preparation time, have made Marin insecure and a little bit frustrated.*

*Being in contact with other people and children living with T1D has helped him the most. For my husband and I, the biggest challenge was to get the right information about nutrition and how to care for our son's glycaemic levels. The professional education we received from the hospital was incomplete and insufficient.*

*Our diabetes association, the experiences of other parents and people living with T1D, support in the area of nutrition (privately) and access to medical literature are all tools that have helped us in confronting the diagnosis and its consequences.*

### **MAREN, MOTHER OF SARAH-LÉONIE LIVING FOR 4 YEARS WITH T1D, GERMANY**

*When Sarah-Léonie was diagnosed, I stumbled and fell deep for two years. The time of the pandemic was obviously not helping. We had to rearrange our whole (daily) life; nothing seemed to be as before. I did not feel up to taking care of Sarah-Léonie's diagnosis properly which started with a very serious ketoacidosis; 12 hours later she would have been dead. I did not know anything about T1D, wanted to understand this condition in order to manage it not only properly but perfectly, but it was too complex at the beginning and still is complex today four years later. And I wanted to be good for my girl transmitting a positive attitude to her because T1D is now part of her and as such it is important to embrace this condition and work together as a team, with diabetes being something like a family member or a buddy. But being strong the whole time was demanding without sleep and without time to recover and recharge batteries. I call it a tough and exhausting start into this new life for all of us, Sarah-Léonie being the one who accepted it quickest. The most helpful thing to overcome my feeling of overburdening, helplessness and frustration was to work on my own resilience.*

### **KARLOS, BROTHER OF MIA, LIVING FOR 9 YEARS WITH T1D, CROATIA**

*The diagnosis meant a big change in my sister's and all of our lives. At the beginning, seeing her struggle to accept it and to accept that she needed to adapt her life around it, seeing her feel bad because of bad blood sugar levels and knowing I couldn't to turn the situation around, made me worry a lot about her. Just believing that that she could and would find a way to live normally with it helped me mentally.*

### **ELENA, MOTHER OF FRANCESCO, LIVING FOR 10 YEARS WITH T1D, ITALY**

*The main challenges we had to face were to keep going with our normal life projects (holidays, sport, school...) in a safe way. We have always dealt with all the problems by sharing our opinions with Francesco and listening to his point of view and in my opinion, this has been very helpful in addressing different challenges.*

### **MAYA, MOTHER OF A PERSON LIVING FOR 30 YEARS WITH T1D, BULGARIA**

*When my daughter was diagnosed, I was totally disturbed and upset, as this diagnosis was absolutely unexpected.*

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## COPING WITH DIABETES



### MAREN, MOTHER OF SARAH-LÉONIE LIVING FOR 4 YEARS WITH T1D, GERMANY

*My mental health was affected by the pandemic. I tried to analyse what did me good or bad and tried to spare the bad stuff, if possible, out of my daily life. I also started to work on my own resilience and tried to sleep at least a minimum of six hours somewhere within 24 hours. I also tried not to be frustrated or angry about things, measures and procedures I could not influence.*

### LUCIJA, LIVING FOR 19 YEARS WITH T1D, CROATIA

*My mental health was affected during the pandemic. I was trying to keep active as much as possible, trying different home exercises which also helped with managing my diabetes.*

### KEN, LIVING FOR 24 YEARS WITH T2D, UK

*I have suffered with mental health, with depression and stress. As a psychotherapist, I am lucky that I have my peer support supervisor and also relatively good help from friends. Friend support is vital.*

### ROSSITZA, LIVING FOR 28 YEARS WITH T1D, BULGARIA

*Diabetes definitely had an impact on my mental health through different periods of my life, mostly in my early 20s. What helped me the most was support from my family and friends, support from people living with T1D and finding the right psychotherapist.*

### ANTONIA, LIVING FOR 13 YEARS WITH T1D, CROATIA

*Surrounding yourself with supportive and loving people and doing what you love is the best way to deal with light mental health issues.*

## DID YOU KNOW?

- Diabetes increases the risk of severe COVID-19
- COVID-19 may lead to new onset diabetes or worsening of already existing metabolic disorders
- Depressed individuals show a higher risk of developing diabetes and PwD have a higher risk of developing symptoms of depression
- In people living with T2D and in COVID-19 survivors the prevalence of depression is increased
- People living with depression have a more than 30% higher risk of developing diabetes than people without depression



# DIABETES AND ITS IMPACT ON MENTAL HEALTH



## WHAT IS NEEDED TO IMPROVE THE MENTAL HEALTH OF PwD AND THEIR FAMILIES/CARERS?



### SUFYAN, LIVING FOR 32 YEARS WITH T1D, UK

*In the UK, there are lots of policies around diabetes and mental health, but access to HCPs can be a challenge for some. Personally, I don't feel this is an issue for myself, but as a healthcare professional (diabetes doctor) I know that for PwD in general the challenge is that there are not enough psychologists/psychiatrists with a specialist interest in diabetes to support the demand for PwD currently.*

### KEN, LIVING FOR 24 YEARS WITH T2D, UK

*Be aware of what the person is not telling you, look at their demeanour and ask questions. Listen and don't be judgemental. And if you cannot help them, make sure that you can direct or know of someone who can. Sometimes peer support groups can help as others maybe going through or have been through similar episodes.*

### JOÃO, LIVING FOR 42 YEARS WITH T1D, PORTUGAL

*Despite mental health being on the agenda and despite some successful cases, like the Portuguese Diabetes Association which has excellent initiatives, there is no relevant national policy on mental health for PwD. For me, the most useful was contacting other PwD, in particular the youngsters.*

### ELENA, MOTHER OF FRANCESCO, LIVING FOR 10 YEARS WITH T1D, ITALY

*In my country, mental health support is known to be very important in diabetes and so it's reported in every diabetes document. However, it is not provided free of charge as endocrinologist visits are and most people do not use it.*

### ANTONIA, LIVING FOR 13 YEARS WITH T1D, CROATIA

*It is crucial to listen to PwD and take their problems related to living with diabetes seriously. If they are struggling, we should be there for them and offer them support.*

One in three adolescents living with T1D (aged 10-20 years); one in three adolescents and young adults with T2D (aged 13-21 years) and up to 60% of young adults (aged 18-30 years) report elevated diabetes distress, with prevalence rates for depression among young PwD ranging from 17% to 63%.



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## WHAT IS NEEDED TO IMPROVE THE MENTAL HEALTH OF PwD AND THEIR FAMILIES/CARERS?



### VALERIE, LIVING FOR 6 YEARS WITH T2D, IRELAND

*People living with diabetes are often experts about their own bodies and keeping them in balance. As such they should be listened to. HCPs should spend more time listening to patients as part of their regular review. For PwD, the prescription is only the beginning of the story.*

### SUFYAN, LIVING FOR 32 YEARS WITH T1D, UK

*Mental health is one of the cornerstones of health and essential in the management of diabetes. Today's environment and societal pressures place a lot of strain and demands on young people and adults. Living with a condition such as diabetes in addition to this adds a considerable burden. Reducing the burden with treatments that are easy to use and also access to healthcare professional support, including psychological support, is essential. Continuity of care and relationship building is key. Peer support and developing a framework for this is also important. There is a lot of variation within countries and throughout Europe.*

### ANTONIA, LIVING FOR 13 YEARS WITH T1D, CROATIA

*It is crucial to listen to PwD and take their problems related to living with diabetes seriously. If they are struggling, we should be there for them and offer them support.*

### MAREN, MOTHER OF SARAH-LÉONIE LIVING FOR 4 YEARS WITH T1D, GERMANY

*In my eyes, resilience is an important key to mental health but far too many people don't even know what resilience is about. Concrete offers with regard to mental health and dedicated resilience programmes for children living with T1D, their families and caregivers should be launched all over the country. And it is important to take the whole family on board psychologically as all the family members' needs, problems and challenges are intertwined.*

## DID YOU KNOW?

- Almost one in four adults with T2D experienced depression.
- Diabetes is two to three times more prevalent in people with severe mental illness
- Depression can negatively impact PwD's self-care, diabetes management, self-efficacy, cognitive outcomes, and medication adherence, increasing the risk of developing diabetes complications
- Introducing new practices among HCPs to take into account people's emotional needs can enhance HCPs' efforts to address psychological health in adults with diabetes

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## WHAT IS NEEDED TO IMPROVE THE MENTAL HEALTH OF PwD AND THEIR FAMILIES/CARERS?



### JOÃO, LIVING FOR 42 YEARS WITH T1D, PORTUGAL

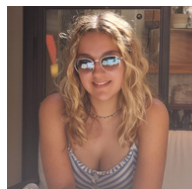
*I would like to emphasise the critical importance of addressing the mental health needs of people with diabetes and their families. By addressing mental health, we can significantly enhance the well-being and quality of life for PwD. Living with diabetes can be an overwhelming experience.*

*The daily management of blood glucose levels, medication, dietary restrictions, and potential complications can lead to significant stress, anxiety and depression. Furthermore, the burden extends beyond the PwD, it affects their families and caregivers who may also experience emotional distress and concerns*

*Here are a few key areas that require attention and improvement:*

- **Integrated care:** there is a need for integrated care models that bring together diabetes management and mental health support. By incorporating mental health professionals into diabetes care teams, they can address the psychological impact of diabetes more effectively.
- **Awareness and education:** policymakers and HCPs should work towards increasing awareness and education about the mental health challenges associated with diabetes. By promoting understanding among PwD, their families and HCPs, we can encourage early recognition of mental health symptoms and facilitate appropriate interventions.
- **Accessible mental health services:** it is essential to ensure that mental health services are accessible and affordable for PwD and their families. Expanding mental health coverage, reducing barriers to care, and increasing the availability of mental health professionals can help bridge the existing gap between mental health needs and resources.

**IDF Europe would like to thank each and every person who took part in our Mental Health Campaign. By working together, we can reduce the stigma and work towards a more holistic approach on diabetes management.**



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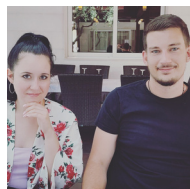
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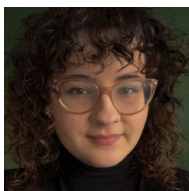
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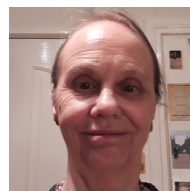
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SUFYAN



VALERIE



## SOURCES

- *The interface of COVID-19, diabetes, and depression*
- *The prevalence of comorbid depression in patients with type 2 diabetes: an updated systematic review and meta-analysis on huge number of observational studies*
- *Living with diabetes alongside a severe mental illness: A qualitative exploration with people with severe mental illness, family members and healthcare staff*
- *Is it time to consider depression as a major complication of type 2 diabetes? Evidence from a large population-based cohort study*
- *ISPAD Clinical Practice Consensus Guidelines 2022: Psychological care of children, adolescents and young adults with diabetes*



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