We Are So Glad You Are Here!

Dr. Nicole Johnson has worked in diabetes for over 18 years. She is most well known for her time as Miss America 1999. Nicole has gained a reputation for her research focused on quality of life and psychosocial issues. She runs a research group at the University of South Florida.

Lorraine Stiehl has worked in diabetes for 30 years, beginning when she married Chris — he has had T1D for over 55 years! Her career has spanned academic medicine and non-profit management. She has expertise in clinical trials, fundraising and living with a T1D for over 30 years!

Dr. Stephanie Melton has worked in diabetes and nutrition science for over 10 years. With degrees in medical anthropology and public health. She teaches Diabetes Partners and Diabetes Prevention classes regularly and conducts research at the University of South Florida.

How Are Partners Doing?

- Exhausted
- Discouraged
- Guilty
- Angry
- Isolated

It’s Not About the Nail

The Impossible Diabetes Caregiver Scenario

Harping Helping Abandoning

Partners Are Fearful

- What will happen to their loved one’s health
- Wondering if they are being too overprotective or overbearing
- Wondering if they are doing enough
- Worried they don’t know enough about diabetes to help
Literature Supports This

Marital adjustment, intimacy, & quality of life are all positively correlated\(^1,2\).

Marital adjustment and intimacy tends to be associated with better blood glucose control\(^1,2\).

Chronic distress results in increased conflict and less relationship satisfaction\(^3\).

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Emotional Strain

- Fear of severe low blood glucose
- Emergency lows were described as traumatic
- Long-term complications
- Perceived shortened life expectancy and grief of a “normal” life
- Assume that diabetes will impact major life decisions including having children, and jobs
- Feeling helpless

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Describing Support in Couples with Diabetes

Family & marital support is associated with:

- Better treatment adherence\(^4\)
- Better adaptation to illness\(^5\)
- Better blood glucose control\(^2\)

Social Support vs. Social Control\(^6\)

(Helping vs. Nagging)

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The Caregiving Role

- Primary source of diabetes information was their PWD or Dr. Google
- 90% had intervened in a severe low blood sugar episode, but only 26% had ever received ANY kind of diabetes education
- Roles vary—most are hands-off
- Avoid replicating parental role
- Diabetes Detective

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From Our Research

- Formative, qualitative research
- In-depth interviews with 19 partners of PWD
- Investigated emotional strain, factors affecting caregiving role and coping

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The Conflict Cycle

[Diagram showing the cycle of worry, questioning, conflict, rebellion, and interpreted as nagging]
Challenge Areas for Partners

- Food
- Managing low and high blood glucose episodes
- Diabetes burn-out/depression
- Being a diabetes detective
- Balancing support and independence
- Trust
- Communication styles and conflict

Coping

- Balancing support and independence of spouse is challenge
- Communication strategies
- Negotiating caregiver role—trial and error
- Finding positive aspect of diabetes

Goals for Building a Successful Relationship

- Constructive Conflict Management
- Friendship/Intimacy & Positive Affect
- Shared Meaning & Goals

Diabetes in Real Life – Lorraine’s Story
Practice Pearls

Partners are forgotten members of the diabetes team

They want more education

• The basics
• Severe lows
• Glucagon
• Sick days

Lack of support for partners within clinical environment or in communities

Understanding the personal and diabetes histories of your patients:

• Age at diagnosis/Duration of disease
• Experience with the parental relationship
• Technology use
• Roles within the family

Education Strategies

Invite partners in sessions when appropriate

Provide materials to share with partner

Ask about how partner helps—strategize specific ways

• How can you help him/her help you? What tasks can he/she help with? What situations, they did this...

Suggest establishing communication rules

• When is it ok to ask about your blood sugar?
• What are your rules of engagement during an argument?

Suggest counseling when appropriate

Meet Martin and Amanda

Life with type 1 diabetes: three important facts every spouse or partner should know

1. Type 1 Diabetes is Not a Death Sentence

Every week that your partner may be defined as a list of complications, like blindness, kidney, amputation, and the like! Well, things have changed dramatically over the last few decades. Thanks to new diabetes care approaches, more and more people with T1D are living long and healthy lives. With good care and effort, we are seeing that the risks for these many complications are diminishing. Bottom Line: Don’t worry unnecessarily. Thanks to 21st century technology and medical care, T1D is not a death sentence. These troublesome long-term complications are now often preventable. While no guarantees are possible, with good care and effort, odds are good that your partner will enjoy a healthy life!

2. The Psychological Effects of Hypoglycemia

When your partner’s blood glucose is too low, he or she may not be thinking clearly or usual. Your partner may become moody, nervous, easily agitated, and/or find it hard to concentrate. Even worse, your partner may not even realize that they hypoglycemic episode is occurring. Why? First of all, it may be occurring during the night, or early morning, or early afternoon. Second, when hypoglycemia is occurring, the blood glucose levels may be too low to produce any symptoms. And third, to be alert with your partner after, but not during, a low! What is most important is that you and your partner have an agreement in place regardind what to do if hypoglycemia is happening.

3. The One OA

T1D is a 24/7 condition. It is an ongoing, on-going condition, in which your partner is responsible, without your blood glucose, the blood glucose levels must be maintained. What is great about T1D is that you can make changes to your glucose levels. Some have found ways to carry this disease, but others have not. If you are new to this, your partner may worry about getting diabetes, please know that you can always try to fix it. But, it can happen if you let your partner know that you are taking the time to understand and accept. In the meantime, you must be very kind to your partner, dealing with diabetes can be a stressful time. If your partner needs a break or a moment, be as supportive and understanding as you can.
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Find more of our work at www.diabetesempowerment.org

References


Life partners are influencing the outcomes of your patients. Let's bring them into the conversation about living positively with diabetes.