How can I help my children understand my chronic autoimmune conditions and their management?

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I live with systemic lupus erythematosus (SLE) and antiphospholipid syndrome (APS). Over the past two years, particularly with the uncertainty around covid-19 for immunocompromised patients, I realised that I had rarely included my children directly in conversations about my health.

My health conditions are largely invisible, which can be both a blessing and a challenge. To my children, their mama looks just as “well” as other parents they meet. However, when a flare or acute illness presents, some of the health challenges are very visible and frightening for my children, as it must be for others who have a parent living with a lifelong, chronic condition.

My children have helped me with calling an ambulance, and have seen me acutely unwell in the emergency department on more than one occasion. One particular event distressed my young son so much that there were a lot of tricky questions afterwards that we needed to navigate: “Will this go away for you?”, “Are you going to die?”, “Will this happen to me too?”

This experience made me consciously reflect on conversations we have with children, particularly young children, about their parents managing chronic conditions. How much information should I give them? How do other parents with chronic autoimmune conditions have these conversations with their children? How can I be honest about my health, without frightening them?

While new studies of diagnosis and management are critical for conditions like mine, so too are studies that support patients to best live the lives we have right now. For me, involving and supporting my children are central to this. The inspiration for this piece came courtesy of an episode of children’s TV programme Operation Ouch, where a demonstration of viper venom and a blood sample was central to a conversation about clots. My daughter played the segment for me on her iPad, with the question, “Mum! Is this what happens to your blood?”

She asked me to show her the medication that manages clotting, and this extended to a broader conversation about the other medications I take. Finally, she asked if she could help me by sorting my medications (under supervision) into the weekly pill organiser I use. She asks about doses, changes in colour, and type. Like clockwork every Friday night, she reminds me of her chosen job. I can’t say I would have planned explicitly to include her in this way, but it makes her feel she is involved, helping, and informed—and that seems to be really valuable to her at this age.

To an extent, my conversations (and increasingly inclusive approach to my health) with my children have been ad hoc. Looking back, I would have welcomed ideas from other patients about how to start these conversations, particularly before major events prompted distress and uncertainty for my children. I still do, as I don’t know what is to come.

Qualitative research and insights from other patients living with my autoimmune condition, and their experiences of supporting their children across childhood and adolescence, would be invaluable. Existing literature suggests that living with a parent who has a physical or mental illness can impact quality of life and wellbeing in children.1–3 Many of these findings understandably focus on contexts that involve terminal illness or life threatening conditions such as terminal cancer, or more recently, covid-19.4–6

While these studies offer some insight into the experiences of parents and children in life threatening circumstances, they may not be as relevant to parents such as myself, who have lifelong chronic conditions. These perspectives are more limited. Considering these insights could add important context and support material for future parents navigating lifelong chronic conditions, particularly given associations with wellbeing and quality of life for the children themselves.

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