



PRACTICE

WHAT YOUR PATIENT IS THINKING

Sibling and family caregivers

A sibling explains how recognition of the care his family provides for his brother can make things better

Nathan Grant

My twin brother has a rare, chronic condition called mucopolysaccharidosis II, also known as Hunter's syndrome. Although my brother sees many medical specialists, he receives most of his care at home from family members. My parents and I assist him with daily activities, including eating, bathing, and toileting. We also provide therapy at home, which my brother has benefited from a great deal. Caring for my brother requires time and dedication. It can be challenging.

As my brother gets older and bigger, it is becoming harder to take care of him. Also, as my parents age, they struggle to fulfil their caregiving responsibilities. They have no day off.

The burden of care giving

Care giving comes with physical, emotional, and financial challenges. My brother requires constant supervision, so someone must always be with him. When my father goes to work and I go to school, my mother provides my brother's care. Consequently, she does not have much time for other things such as self care, and she is often physically and emotionally exhausted. And because my parents must spend time helping my brother, they often do not have much time to spend with me. My story exemplifies how illness can affect an entire family. If my parents and I are not at our best, it is my brother's health that suffers.

Recognising caregivers

My brother is non-verbal so healthcare professionals must communicate and work with my family to make decisions regarding his care. However, many of my brother's healthcare providers focus on his symptoms and do not consider my needs or those of my parents. They rarely ask us how we are doing as caregivers.

Although my brother's health is the priority, my parents and I are responsible for giving the care that providers recommend. When providers focus on my brother's symptoms and do not consider my family's experiences, they can often give recommendations that are not feasible. At a recent appointment, my family was given a three page list of additional recommendations to follow, including more drugs to give my

brother. My brother does not like taking his drugs and often becomes confused and angry when made to do so. This makes it difficult to provide care that adheres to all the doctors' recommendations. When doctors do not inquire about our experiences as caregivers, they do not know about these struggles and can continue to give recommendations that are not helpful.

A lack of consideration of my family's needs harms our ability to provide effective care for my brother. It would help if medical providers engaged in shared decision making that includes the entire family when providing treatment to patients.

How are you?

I wish healthcare providers of all specialties spent more time asking how my parents and I are actually doing. It would help to hear professionals ask, "How are you? What are your current caregiving responsibilities? Are these recommendations feasible?" In addition to acknowledging caregivers' needs, it can also be helpful if healthcare providers referred caregivers to resources for support as needed. Recognising and supporting caregivers can help them to provide better care, which may promote better health outcomes for patients.

In addition to the limited support for caregivers within medical institutions, healthcare providers often exclude me from discussions about my brother and only address my parents. Although I am a sibling, I am involved in my brother's care and I anticipate assuming more caregiving responsibilities in the future. I would like healthcare providers to recognise that siblings, of all ages, may be involved in the care of their brother or sister and may be in need of support themselves. Including me in discussions about my brother can help me better understand his condition and how to care for him, and will help foster a smooth transition of care when my parents are no longer able to serve as my brother's primary caregivers.

My brother's health affects my entire family. Increasing support for caregivers within medical institutions can make a positive difference to how a family provides care for a family member.

What you need to know

- The health of patients can affect that of the caregivers, and the wellbeing of caregivers can affect patients
- Acknowledge and deal with the needs of all caregivers, siblings' as well as parents', when providing treatment to patients
- When asking carers to do more, explore the feasibility on top of their other caring duties

Education into practice

- What insight does this article offer you into care giving as a family, and the role of siblings?
- To what extent, and how do you involve siblings in discussions about care and health plans? How could you do this more effectively?
- When creating or adapting plans for a person's care, how could you better explore whether family caregivers are able to carry out added suggestions?
- How do you usually offer support to caregivers? What resources can you direct them to? What other resources might be available to you?
- Is there anything else you may think about or act on differently having read this article? What understanding does this article offer you into care giving, and the role of siblings?

These questions were developed by the editors and reviewed by the patient author

Further information

Parents Helping Parents. Resource for parents and patients. www.php.com

Family Voices. Resource for parents. www.familyvoices.org

Siblings with a Mission. Resource for siblings. www.siblingswithamission.org

The Sibling Support Project. Resource for siblings. www.siblingsupport.org

Sibling Leadership Network. Resource for siblings. www.siblingleadership.org

Many support groups and organisations provide diagnosis specific resources for patients and families

Competing interests: NG is an unpaid member of Siblings with a Mission, which he recommends as a resource.

Patient consent obtained.

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>