

Family Well-Being in Psoriatic Disease

Caring for the Caregiver



Who is the caregiver?

A caregiver is anyone who is involved in caring for someone who needs help. Often the role of a caregiver is associated with children, the elderly, and people with disabilities.

Caregivers may be health professionals, social workers, family members, or friends. **This can be a demanding job, both physically and psychologically, but often overlooked.**

Balancing care duties on top of an individual's own personal and professional life can be challenging. The lack of protection and support for caregivers is an added burden.

Caring for a child

- The main caregiver is usually a parent.
- In heteronormative families (with a father and a mother), mothers are usually the main caregiver. This results in an uneven burden compared to fathers.
- The main caregiver often gives up on professional goals and ambitions to care for the child.
- If there are other children, there can be feelings of guilt and frustration because of the unequal time spent caring for the sibling with psoriatic disease.

Caring for an adult

- The main caregiver can be a parent, a sibling, a child, a partner.
- The caregiver not only supports with everyday tasks, but also with managing the medical journey, and dealing with various challenges associated with psoriatic disease, including mental health.
- This role may result in physical and emotional strain for the caregiver, including burnout and self-care neglect.



How to champion your own well-being?



Seek support from patient organizations or support groups, where people with similar experiences can meet and talk to each other, can be extremely empowering and a way to find practical coping strategies.



Demand education and training for caregivers, teaching how to best manage the disease, stress and flare ups, and care for the family member.



Challenge healthcare providers to ask for the needs and evaluate the caregivers' well-being during medical appointments. Several validated questionnaires that assess the quality of life of family members and caregivers are readily available. These facilitate the quantification of the burden of the disease, and may facilitate the referral to appropriate help if needed.



Demand more flexibility at the workplace. This includes caregiver leave and flexible work hours, reducing the stress of juggling work and caring for the family member.

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I would say there is a difference between being a caregiver for a child versus an adult, because more people have kids. It is just more relatable.

Caregiver, UK

The thing that caregivers also need support, which has to be created firstly from the doctor. The doctor needs to be informative and helpful to the caregivers as well, so that the patient doesn't take the wrong road.

Caregiver, Greece

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Call to action

We call for the improvement of caregivers' well-being.

- **Involve the caregiver in care planning and disease management:** When actively included in the care plan, caregivers can help monitor and manage the disease.
- **Educate caregivers:** Most caregivers feel worried about making the wrong decision and negatively affecting their family member's condition. Providing reliable and trustworthy information empowers caregivers and gives them the tools and knowledge they need to succeed in their role.
- **Demand healthcare provider education:** Advocate for healthcare professionals to receive training on how to work with caregivers, understand their challenges, and recognize that caregivers may need additional support and resources.
- **Drive policy reforms:** Work with policymakers to create programs that protect caregivers, such as paid caregiver leave and mental health support programs.
- **Organize awareness campaigns** about the role and struggles of caregivers. Increased public understanding can lead to greater empathy and support for caregivers at work and in the community at large.





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