Advocating for Family Well-Being in Psoriatic Disease

The impact of psoriatic disease on the family

At least **60 million people** live with psoriatic disease (2-3 % of the world's population). Despite the high prevalence there is still a widespread lack of awareness and information about what the disease is. Many still think the disease is contagious or that it is a skin disease. But psoriatic disease is more than skin deep, and the impact goes beyond the physical symptoms, affecting mental health, well-being and more.

The disease, its impact on everyday activities and well-being, and the prevalent stigma from society also negatively impacts the family. **Approximately 90 % of family members report that the disease negatively impacts their quality of life.**

It is unquestionable: we need to **stop the stigma** and develop tools and strategies focused on improving the well-being of the family.

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> *When her condition became severe, it was the time for me to become her caregiver.*
>
> ***Sibling, Greece***

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> *We had to leave home, they thought my brother was going to infect someone. They don't want to see us. They think it would affect everybody in the house.*
>
> ***Sibling, Ghana***

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> *The diagnosis had a profound effect on the family, because the awareness was lacking.*
>
> ***Sibling, Pakistan***

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> *If my child is having a sudden flare and he needs a bit more attention then obviously he will get more attention than the other children. I know they are not getting the attention they need. Its a continuous thing to juggle.*
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> ***Parent, Malaysia***

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> *It is super hard mentally and physically, especially for my mother.*
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> ***Child, Philippines***

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> *The stigma associated with it is still massive. The way people ask questions is almost insulting, because they are also coming from a place of absolute no knowledge or awareness.*
>
> ***Sibling, South Africa***

Why raise awareness and fight stigma?

Even the simplest everyday activities can involve extra challenges for the family and caregivers of people living with psoriatic disease. These include, for example, managing the household chores, attending social events or gatherings, balancing work and the care for the family member, managing the family budget and being able to afford the products needed to manage the disease on top of the household and family needs.

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> *If we can just normalize the condition, like if people have acne you don’t go up and ask them what’s wrong.”*
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> *Parent, Malaysia*

> “
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> ***As a society we don’t talk about psoriasis. There’re lots of things we don’t talk about, I find skin conditions just don’t get spoken about. Things like eczema, etc. I think doctors need to approach it the same way a cancer doctor would.***
>
> ***Sibling, South Africa***

Still today there is an engrained stigma against psoriatic disease, mostly caused by myths and lack of information. In various settings, people living with psoriatic disease and their family can experience:

Whispering, and odd or inquisitive looks from others, independently of the country and level of education.

Stigmatization when attending public spaces and events.

Lack of empathy at the workplace, especially for caregivers, who may need to take extra time off to care for the person with the disease.

Supporting the Family, Together

Family members of people living with psoriatic disease can be supported and support each other in different ways, both practically and emotionally.

Learn about psoriatic disease: Understanding the disease is essential to be able to offer the right help and support, but also to educate others and advocate for the disease.

Learn what are the disease triggers for your family member: Triggers and disease management can look very different in different people. Understanding individual stressors that can trigger a flare up may help managing the disease.

Join support groups: Meet people in the same situation can be very powerful, help fight isolation, strengthen the sense of belonging to a community and receive first-hand practical advice from other members.

Create a supportive home environment: Accommodate for mobility or physical limitations, engage on and promoting a healthier lifestyle (for example eating a healthier diet and encourage regular exercise) that will help maintain a healthy weight, and avoiding activities or situations that potentiate flare ups.

Encourage caregivers' self care: Caring of someone with a chronic and debilitating disease can be exhausting, but it is important to take time for the caregivers' own well-being.

Provide emotional support: Psoriatic disease is associated with anxiety and depression, especially during flare ups. Be patient and understanding, offer reassurance, and encourage seeking mental health support when needed.

Become an active participant of the family member's medical journey: When possible, being involved with the medical appointments can help reduce stress and make informed decisions on disease management.

Be mindful of the time spent together as a family: Have family routines and do activities together, whether it is sharing a meal, going for walks or other activities.

Resources for Families

When an individual receives a diagnosis, it affects the entire family. People face many hurdles when looking for information about the disease and how to manage it. Trustworthy information can be found in:

- Your doctor, nurse or other health care professional
- National and international health organizations
- Patient organizations
- Psoriatic disease support group (local and international groups)
- Peer-reviewed medical journals and national disease-specific magazines

> ***The patient organization gave us a feeling of safety and that the information we get is truthful.***
> ***Partner, Peru***

CALL TO ACTION

To stop stigma we need to spread information to make psoriatic disease known to all.
An educated and informed society increases acceptance and reduces the stigma against those affected by psoriatic disease.

It is time to make the world aware of psoriatic disease!

We call for the promotion of public education in several ways:

- Create materials that explain psoriatic disease and raise awareness of the impact of the disease on the family.
- Distribute educational materials to primary healthcare facilities (available for example in waiting rooms or halls) and schools, hosting short information sessions.
- Disseminate awareness campaigns in media (billboards, television, radio).
- Support local patient associations with their advocacy efforts.

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