

THE INTERNATIONAL PAH PATIENT AND CARER SURVEY ASKED ABOUT THE BROADER IMPACT OF THE DISEASE ON THE LIVES OF PATIENTS, THEIR FAMILIES AND THE PEOPLE THAT CARE FOR THEM

1 WHO TOOK PART IN THE SURVEY?

455 PAH PATIENTS AND CARERS PARTICIPATED



2 WHAT DID WE FIND - IMPACT OF PAH ON PATIENTS

"I would describe PAH as being like going in a car which won't go over 10kph." – Patient

PAH HAS AN IMPACT ON PATIENTS' PHYSICAL ACTIVITIES

83% of patients have difficulty climbing stairs

Over half of patients find it harder walking a short distance

Almost 3/4 of patients have difficulty carrying out errands such as food shopping

85% of patients report that their employment is affected by their condition

WHAT ABOUT SOCIAL AND EMOTIONAL WELLBEING?

PAH can cause feelings of:

Frustration Anger Worthlessness
Feeling misunderstood
Low self-esteem Isolation



Over one third

of patients wanted more information on the emotional impact of PAH, including depression

Patients often experience a wide range of emotions as a result of living with PAH which go beyond the physical challenges of living with PAH. Patient organizations can be a great source of emotional support for patients, as they provide advice and information about coping with these feelings

3 WHAT ABOUT CARERS?

HOW ARE CARERS AFFECTED?

"I no longer have hobbies as it is not feasible with being a carer...it takes up all my time." – Carer



One in three

carers have to stop or change their work to care for someone with PAH

Over half



of a carer's time each month is spent caring for their relative which can leave carers feeling isolated



87%

of carers want regular updates on the health status of their relative

Carers tend to prioritize the patients' emotions above their own, but they can also feel stressed, frustrated and isolated by the challenges that PAH brings. Therefore, it is important that the emotional needs of carers are also considered so they can continue to support their relative or partner

4 WHAT CAN WE DO BETTER?

1. Take a **multidisciplinary** approach to care considering the **emotional** and **social impact** of PAH, as well as managing the physical symptoms
2. Build **closer working relationships** between healthcare professionals and patient organizations
3. Provide patients and carers with access to **the right information at the right time** for them
4. **Recognize the needs of carers** and the importance of tailored support for them