

## Living With Primary Ciliary Dyskinesia: An Islamic Perspective

*Prophet (peace be upon him) said:*

*"There is no disease that Allah has created, except that He also has created its treatment." (Sahih Al-Bukhari, book # 71, Hadith 582, narrated by Abu Huraira)*

PCD is short for Primary Ciliary Dyskinesia and is a rare, inherited condition. This leaflet is aimed at people of Islamic faith living with or caring for people with PCD.

Coming to terms with the fact that you or your child has a life-long condition can be challenging in many ways, and it can be helpful in your life to talk to the people around you. For some, this may be family or friends, for others it may be their faith or community including religious leaders (such as your local Imam). Everyone is different, so it is important to find the right people in your life that can help and support you. As the symptoms of this condition may not be apparent to other people, it may be difficult for others to realise how you are feeling, how PCD affects your day-to-day life and the role you have in your community.



**Family and friends** can help with coming to terms with PCD. It can be helpful for those around you the most, to understand what it feels like for you or your child to have PCD. This can help them understand how best to support you.

**Faith** can help you on a spiritual level to find strength and coping strategies as well as giving you comfort. Your local Imam or Muslim Healthcare Chaplain can be contacted to explore any concerns or queries about your PCD and any treatment that may impact on your faith.

**Your clinical team** can help you to understand how PCD will affect you. Your PCD team will work with you to help you achieve the best outcomes for your health and quality of life. They are here to support you in learning how to live with PCD.

There are many health professionals to support you through your journey. They will work with you and your family to understand how PCD symptoms affect you/your child and what your priorities are; to build a plan to improve your quality of life and help you work towards you/your child's life goals. This will be documented following your annual review in a personal PCD management plan.

Talking to your clinical team early about things that might worry you can help to find solutions more quickly and reduce stress. This could include understanding treatments and balancing them with faith rituals such as:

- treatment during Ramadan
- exploring options for alternative treatments for example-
  - immunisations/vaccines, such as animal free options.
  - medications that fit within the dietary requirements of your faith, Such as medicines that are gelatine-free

### Who is in your PCD Team?

Your PCD team will work **together** with you to help you achieve the best outcomes for your health and quality of life. Your teams will likely include:

**Respiratory Consultant:** This person takes overall responsibility of you/your child's care and will look at your results, and your physical health pulling together information from you and the clinical team to aid them in treatment recommendations.

**Ear, Nose, and Throat (ENT) Consultant:** Takes responsibility for you/your child's hearing/ears, sinus/nose and throat care and will look at your results, and your physical health pulling together information from you and the clinical team to aid them in treatment recommendations.

**Physiotherapist:** Working together with your physiotherapist will help you to achieve good health outcomes in the future. They will offer specialist advice on airway clearance and exercise to maintain optimal lung health.

**Nurse Specialist:** Your PCD Nurse is often your first point of contact. They will help you learn to manage PCD and live with you/your child's condition. They will act as a link between you and the rest of the MDT to access and co-ordinate the best possible care for you/ your child.

**Dietitian:** Your PCD Dietician will help with all your PCD related diet and nutritional concerns. The team will refer to the dietitian if advice or support is required.

**Psychologist:** It can be difficult living with a long-term condition. If you feel it would be of benefit, the team can refer you or your child to the psychologist to think more about your journey with PCD and the impact on you/your child's emotional wellbeing. This can help support you with your wellbeing and with personalised strategies to help adjust with living alongside PCD.

**Administrator:** The PCD Administrator is responsible for booking clinic appointments and helping to co-ordinate required tests. They also help to support with written and phone communication both prior to and following your clinic appointment and help to ensure any results or information required is collected in preparation for your review.

**Translation:** Your team will have access to a range of translation services. Medical words can be difficult to understand if English is not your first language. Please discuss with your team if you need help with translation in your clinic appointment or with your clinic letters.

## More information

There is a great deal of information about PCD on the internet but not all of it is from recommended sources. If you read anything that worries you, please discuss with your clinical team. For more recommendations, please speak to your clinical team.

PCD Support UK is a UK based support group is run by people with or carers of those with PCD. Their website contains lots of useful information on PCD and they often run information and support sessions. The PCD support group help to inform and support your team with the PCD persons perspective and play a very active role in framing PCD services across the country: <https://pcdsupport.org.uk/>



This leaflet was created by the PCD Support UK & National PCD Service Diversity Working Group. The group comprises of adults with PCD and parents of children with PCD from Muslim communities, an Imam and NHSE National PCD Children's and Adult Management Teams.