

# Information for young people starting secondary school

The transition to secondary school may seem a little daunting for many different reasons, but it doesn't have to be: there's lots to look forward to! If managing your PCD in school is one of your concerns, we're here to help make it as easy as possible.

This guide has been written by parents of children with PCD. Hopefully you'll find the information in this booklet helpful, giving you an idea on what to expect and what questions you might want to ask your new school.

## Questions you may want to ask

- Who will my form tutor be?
- Is there a private space I can use if I need to do physio?
- Does the school have a pastoral hub (or similar)?
- Is there a pastoral manager and/ or a school nurse?
- Will I be able to have a pass to leave the lesson?
- What is the school's procedure for dispensing medication?
- What sports can I do?

There will be lots of new things to get used to at secondary school, so it would be useful and probably more reassuring if you could ask these questions before you start. You could even ask these questions on a taster day or contact the school separately and ask to speak to the head of year.

At primary school it's likely you only had one teacher, but at secondary you'll have a different teacher for each subject. Your form tutor will be your first point of contact, the person (at least at first) who will know you best. Try to speak to your form tutor before you start school, or if you'd prefer, ask your parents to arrange a meeting that you can also attend. This will help the school get to know you and you can plan how to manage your PCD in school together, in a supportive environment. Your form tutor will be a good person to talk to in school if you have any worries that aren't related to a particular subject.

Most schools will have a pastoral hub, but it may be called something different. This is a place where you can go if you want someone to talk to, need some space, or this may be an area where you can do your physio in private. If it's a

large school they may also have a pastoral manager, again this is someone you can talk to if you have any concerns or any additional needs relating to PCD. Many schools will have a school nurse. We encourage you to let the school nurse, your head of year, and your form tutor know about how PCD affects you and what adjustments might make your time at school easier.

Being at secondary school will mean getting used to a new routine. Early starts, getting the bus, organising what books you need, and fitting homework in, are some of the new things you may have to juggle. Obviously, you'll have to do all this and still manage your PCD. This will include things like doing your airway clearance (physio) regularly, attending your hospital appointments and taking your medication. Keeping healthy is really important if you have PCD, and it will help make sure you are well enough to take part in 'fun' activities, like school trips, in addition to staying on top of your day-to-day lessons. We know it isn't easy and might feel overwhelming at times, but you should try to put your health first.

'There are lots of people to talk to if you are finding things difficult, such as your parents, someone in school, or your healthcare team. Your PCD team might have a psychologist you can speak to, and your school should have a counsellor you can see. If you find it difficult to ask for help when things are hard, it might be helpful to think together about the early signs other people might notice when you are struggling (e.g., seeming more tired, spending time alone, seeming irritable, or quieter; this will be different for everyone). If your parents/teachers know the signs to look out for, then they can tell when to ask you if you need some support. Looking after your mental health is an important part of staying well with PCD.

If you're on medication, it's important to ask what the school's procedures are for dispensing it. Even though you may feel old enough to manage this yourself, schools will generally insist that medication is handed in to a school nurse if they have one, or reception, so it can be stored and administered correctly.

Keeping your airway clear when you have PCD is really important. If you tend to get a runny nose or you cough a lot and you feel self-conscious about blowing your nose or coughing in front of others, you may want to ask for a pass to leave the lesson. A quick bathroom trip to clear your chest and nose might make you more comfortable and could make it easier to concentrate. 'Better out than in' is the motto in PCD – it's important not to hold your cough in, as sticky mucus can get trapped in the airways and cause more infections. However, if you are lucky enough to get a pass, make sure you only use this when needed!

## **Being Active**

At secondary school there should be a wider range of sports on offer compared to primary school. Some schools have gyms with a good range of equipment, and there are usually lots of sports teams to join! Exercise is good for everyone and it's especially important for those with PCD, so try to find a sport that you enjoy! Please note however, exercising when you are unwell should be done under the advice of your physiotherapist.

## Absences

We know that schools can have very strict absence policies, which is why we encourage you to let school know about your PCD as early as possible. Try not to worry about any possible absences from school. If you have a hospital appointment, make sure your parents/carers inform the school so this can be recorded as a medical appointment. If you have a longer absence or a planned hospital stay speak to your teachers so they can set you some work, so you don't have to worry about getting behind. Only do the work if you feel up to it. If you're unwell make sure you take the time to recover properly and ask your parents/carers to keep the school informed. When you are back at school, make sure you speak to your teachers for help with catching up.

As you get older and begin doing official exams such as GCSEs, you should make sure that your school notify the exam board of any 'extenuating circumstances' that may have affected your progress. This won't include occasional days off, but longer hospital stays are important to mention. Exam boards and universities are used to taking long-term health conditions and disabilities into account, but they will only know about how your health has affected you if your school make sure to officially mention it.

## Vaping, smoking, and drugs

The subject of drugs, smoking and vaping may be discussed in lessons or with your friends. All these activities are extremely harmful and can have irreversible effects. Vaping is becoming increasingly popular with young people, but it's considered very dangerous. In PCD, vaping is likely to cause significant harm and is not advised. It's important to remember that vaping is not the same as nebulising: vaping is coating the lungs in potentially harmful chemicals.

The following video may help: [Vaping: The Facts \(YouTube\)](#)

You may find your friends and other pupils' experiment with taking drugs, smoking or vaping. We know it can be difficult to say 'no' but looking after your health is the main priority. There is lots of advice online on ways to deal with these situations if you are concerned.

This video is suitable for age 11 onwards: [Honest information about drugs | FRANK \(talktofrank.com\)](#)

# Advice for Parents

Starting secondary school is a big transition for your child. It can feel overwhelming having new commitments and a new routine to adjust to, whilst juggling their treatment and living with PCD. It may be helpful to check in with your child more regularly throughout this time to explore how they are feeling about this and whether they would benefit from any additional support.

If your child finds it difficult to ask for help when things feel hard, it might help to sit down with them when they are feeling well, and think together about the early signs you might notice when they are struggling (e.g., seeming more tired, spending time alone, seeming irritable, or quieter; this will be different for everyone). You can then make a plan to check in with them when you notice any of these signs, to see if they need any extra support.

It is important for you to choose a school that meets your child's educational and welfare needs. If possible, find a school that is close to home or is easy for you to collect them if they are unwell or need to attend a hospital appointment. Before your child starts at the school, arrange to meet the headteacher, head of year and school nurse to explain how PCD affects your child. Speak to your PCD team if support is needed.

If your child has been having physiotherapy during school hours at primary school, ask to speak to your PCD nurse specialist or your respiratory physiotherapist to understand whether they want this to continue at secondary school. Then ask your nurse specialist to arrange a school visit or video call with a nurse and/or physiotherapist to explain what is required. Your respiratory nurse and physiotherapist should also provide information on PCD for the school and teachers to refer to.

## Questions you may want to ask the school

- Find out if the school is willing to dispense medication and what procedures are in place to ensure your child gets their medication.
- If your child has hearing loss, it may be beneficial to ask if they could sit at the front of the class.
- Ask if your child may have a pass to leave the lesson to blow their nose or go to the toilet to clear their chest.
- If your child has special educational needs, ask how they will be supported.
- Are there any other children with PCD or Cystic Fibrosis in the school? If so, it is advised to ask the school to make sure your child is in different classes to minimise risks to both children. Make sure they understand that children with PCD and CF are at risk of 'cross infection' (i.e. giving each other infections) and that this can have serious consequences.

## Absences

Frequently missing school can have a significant impact on your child and family life. Find out what procedures can be put in place for them to catch up or if your child can participate in lessons remotely such as via Google Classroom, Teams etc. You could also ask whether it would be possible to send work home or whether teachers can record their lessons for your child to watch from home. Many young people with PCD have absences from school and this is normal. This can become more difficult to manage when they are in secondary school and particularly when they have started their GCSEs.

If you know they are going to be absent from school, encourage your child to ask the teacher to provide details of the work they will be covering or ask whether they can join the classes remotely if they are feeling well enough. If you have unplanned absences on a regular basis then ask a friend to provide copies of their work/notes as soon as you return to school. If they are doing a course that requires working on the school site such as D&T or Art, they could ask the teacher if they would consider adjusting the pace/expectation of the workload and are supported to catch up in class time.

For a pupil to be considered for concessions at GCSE level, they need to have documented their needs over several years. If your child regularly has time off school due to medical reasons it may be worth talking to the school about how concessions may be applied for at an early stage. It is advisable to keep a record of any absences from school, so it can be presented at the request of the examining board. You can support this evidence with copies of medical letters and a specific letter from your PCD team detailing how this condition has affected your child.

The joint council for the GCSE (standing agreement number four) advises that 'Examining groups are required to take all reasonable steps to enable candidates with permanent, long-term, or temporary handicaps or indispositions to demonstrate their attainments.' This means that under suitable safeguards, a grade can be awarded if a candidate is absent from an exam for legitimate reasons. Additional time may be permitted (normally up to 25%) for all types of examination.

If necessary, a candidate can receive treatment during a supervised break. They can also benefit from extra time during exams and rest breaks or toilet breaks. Arrangements can be made (subject to examining board approval) for candidates to take examinations outside their own centre (i.e., at home or in hospital).

Disabled candidates or those with long-term health conditions may be given additional time to complete course work or assigned a reduced amount of course work. Again, this is subject to the approval of the examining board. Many of the larger specialist hospitals have hospital schools who will be able to give you further information on this subject.

## School Trips

It is important for young people with PCD to experience 'normal' school activities and they should be encouraged to go on school trips. If it is a day trip, make sure that your son/daughter has their medication with them and that they have sufficient food, fluids, (and tissues!) for the day. It is important that the teacher in charge is aware of their condition and that they are aware of any limitations they may have.

If your son/daughter is going on a residential trip, then arrange to meet the person in charge of the trip. It is important that your child continues to do their physiotherapy – you may have to train a teacher and give them written permission to do the treatment, or go with them as a helper (if this can be arranged). You should stress the importance of your child having privacy to do their treatments, though speak to your child first to find out what they would prefer. For example, some young people prefer to have a friend accompany them.

Make sure that they have their medication (including inhaler, nebulisers and physiotherapy adjuncts) with them. They may find it useful to take some nappy sacks to put tissues in that they have coughed into and then they can seal the bag and dispose of it carefully. Depending on how old your child is, you might want to send them on their trip with a 'rescue pack' of antibiotics, for if they become unwell during the trip. Speak to your PCD team to decide what is best, as each individual is different.

# General Information about PCD for Schools

PCD is a rare genetic disorder that affects several systems in the body. It can lead to chronic infections of the lungs, sinuses, and ears. PCD can be considered an 'invisible illness,' so although a child may look well, it does not necessarily mean that they are.

Children with PCD generally have a wet cough and/or a runny nose; however, this is rarely contagious to healthy children. For people with PCD, a cough is essential for moving mucus out of the airways and should be encouraged, especially after exercise. Tissues should be available for the children to cough their phlegm into and blow their nose with throughout the school day. Many children understandably find this embarrassing, so please encourage staff to be flexible about allowing them to have toilet breaks during lessons. Chronic cough can also cause weakened pelvic floor, even in children (and of both genders). It is important not to restrict children with PCD from using the bathroom.

Intermittent hearing loss is common in PCD and can result in recurrent glue ear. Whilst grommets are often used in the treatment of children with recurrent glue ear, in those with PCD they are found to be less beneficial. The treatment of this is therefore to monitor hearing regularly and support this with hearing aids, if required. Whilst the PCD Service will regularly monitor the child's hearing, if you have any concerns with their hearing or notice changes consistent with hearing problems such as unexplained disruptive behaviour, lip-reading, talking loudly, failing to respond when called etc., please let their parents know.

Around 50% of children with PCD have a mirror image arrangement of their internal organs i.e., their organs are on the opposite side of the body. This does not affect the children on a day-to-day basis but might be important information to share in the event of an emergency. In a medical emergency where a defibrillator is required, the placement of the pads should make no difference regardless of whether the child has their heart on the right- or left-hand side.

Trapped mucus is a source for repeated infections and, for some children with PCD, this can result in multiple absences from school. Sometimes children are admitted into hospital for two weeks (or more) for intravenous antibiotics and intensive physiotherapy. During this time, the hospital school will be in contact with you to help ensure the child does not miss out on too much learning. Exams can be facilitated in hospital if necessary. As medical appointments do not count in unauthorised attendance figures, please ensure that the child is not excluded from any attendance award schemes if they only miss school for their hospital appointments.

Those with PCD are more prone to respiratory infections and viruses, and therefore it is important to be sensitive to this. If other children in the classroom have respiratory symptoms, you may want to ensure the child with PCD is not sat beside them, and perhaps keep open a window for fresh air.

Exercise, alongside physiotherapy, is key in helping improve mucus clearance. Children with PCD should be encouraged to be actively involved in physical activities and sports days. All children with PCD are different, and some may struggle to keep up with their peers; we would encourage exercises to be adapted to include those with PCD if needed.

Occasionally, individual children may have asthma, in addition to PCD, and therefore they might need to use inhalers prior to exercise. A small proportion of children with PCD also have associated heart problems and this may impact on their exercise ability. If this is the case, the child's parents will be aware of any limitations.

## **Some of the ways schools can help children with PCD**

- You may need to seat the child at the front of the class facing the teacher to prevent any missed learning associated with hearing loss – please remember hearing loss may be intermittent and can fluctuate even from day to day.
- Encourage the child to clear their nose before doing any class-based cooking/tasting sessions. This is important both for good food hygiene and as their sense of taste can be impaired due to a blocked nose.
- Provide tissues (and a place to clear their nose and chest in private if needed) as necessary.
- Liaise with the hospital school during admissions to help the child keep up with their schoolwork.
- Ensure that children can drink freely to make their mucus/phlegm less thick and easier to clear. This is important especially during hot days.
- Children with PCD should be permitted to go to the toilet as and when necessary. Sometimes a bit of privacy is helpful if children need to clear mucus/phlegm from their chest. This should be actively encouraged, as it is crucial to maintaining good lung health.
- Having a long-term health condition like PCD can impact the socio-emotional wellbeing of children for a variety of reasons (treatment burden, stigma etc.). It is important to be mindful of this and to consider whether there is a role for the school's counselling service in supporting the child.
- Teachers may be unaware that children with PCD usually require treatment at least twice daily, which is time consuming and tiring. Children will often get up much earlier than their peers, and go to bed later as a result. They are likely to have less time available during home hours, and might have disrupted sleep if they experience night-time cough. Although we encourage children with PCD to fully participate in school to the best of their ability, flexibility and understanding are crucial to providing a positive learning experience for children with PCD.
- Some suggestions of how to help with this could be:
  - Consider more frequent rest breaks for children with PCD who are experiencing fatigue, and/or returning to school after a period of sickness.



- Workload pace and expectations should be adjusted for children with PCD who are absent from school due to illness and hospital admissions.
- Protect rest breaks for children with PCD by supporting them to catch up on any missed work within class time.

# Information from [www.gov.uk](https://www.gov.uk) website

<https://www.gov.uk/illness-child-education>

## Illness and your child's education

Academies (unless they're only for pupils between 16 and 19 years old), maintained schools and pupil referral units should support children with medical conditions.

You can ask to see the school's policy on supporting pupils with medical conditions.

## If your child has a medical condition

You or a healthcare professional should tell the school if your child has medical needs.

If your child has a disability, the school must make 'reasonable adjustments' to make sure they are not discriminated against.

## If your child gets sick at school

By law, schools have to provide a space for:

- treatment of sick or injured pupils,
- first aid or medical examinations.

This is usually two separate rooms, both with a sink and access to a toilet.

## If your child cannot go to school

If your child cannot attend because of illness or injury, your school and local council will provide support to make sure their education does not suffer.

## The school's role

- The school should:
- let the local council know if your child is likely to be away from school for more than 15 school days,
- give the local council information about your child's needs, capabilities, and the programme of work,
- help them reintegrate at school when they return,
- make sure they're kept informed about school events and clubs,
- encourage them to stay in contact with other pupils, for example through visits or videos.

## The local council's role

If your child's going to be away for a long time, the local council will make sure they get as normal an education as possible. This could include arranging:

- home teaching,
- a hospital school or teaching service,
- a combination of home and hospital teaching.

The local council must make sure your child continues to get a full-time education - unless part time is better for their health needs.

The local council should also:

- have a senior officer in charge of the arrangements and a written policy explaining how they'll meet their responsibilities,
- make sure your child is not without access to education for more than 15 school days,
- arrange education from the start of your child's absence if it's clear they're going to be away from school for long and recurring periods.

## Further Support and Assistance

If you have any concerns about secondary school, we advise you speak to your PCD teams in the first instance.

PCD Support UK are here if you need support, and please don't hesitate to reach out to our PCD parent representatives by email on [parents@pcdsupport.org.uk](mailto:parents@pcdsupport.org.uk).