

Prader Willi Syndrome Association Ireland
 Carmichael Centre
 Carmichael House
 North Brunswick Street
 Dublin 7
 Telephone: (087) 252 2832 (PWSAI Family Liason Ann O’Neill)
 Email: info@pwsai.ie
www.pwsai.ie



Route Map for Parents and Carers of Children aged 0 – 5 years

This leaflet is an amended version of the PWSA UK Route Map, which was facilitated by Genetic Alliance UK and funded by the Department of Health in England. PWSAI is grateful to PWSA UK for allowing us to use their work.

Health

The following are health issues commonly associated with PWS, which require intervention from health professionals. **Please remember** that PWS is a spectrum disorder, **your child may not** experience all these symptoms.

Age	Health Issue	Professional Involvement
0 - 12 months	Failure to thrive (i.e. low weight gain) - mainly due to poor sucking abilities from birth. Nasal tube feeding can be required. The length of time this is required may vary depending on the child. As the child gets stronger their ability to suck will improve and issues resolve.	Paediatrician. Dietician. Speech therapist for help with sucking and chewing. Baby unit staff. Community nurse.

0 - 5 years	Low muscle tone (hypotonia) Delayed Milestones (however milestones are met! Just in your child's own time) GH treatment and special exercises can help.	Physiotherapist. Occupational therapist. Orthotist (help with shoes and other walking aids).
Age	Health Issue	Professional Involvement
0 – 3 years	Squint (strabismus) in one or both eyes. Can sometimes correct with age as the muscles get stronger. However, may require patching, or surgery.	Ophthalmologist. Orthoptist
0 – 5 years	Thickened Saliva and weak enamel. Can lead to tooth decay. Ensure cleaning twice a day from first teeth and regular dentists checks from an early age.	Dentist.
0 - 5 years	Boys may have undescended testes. Your specialist will recommend the best course of action - often, surgery will be advised.	Paediatrician. Paediatric Endocrinologist.
0 - 5 years	Asthma, bronchitis and other breathing difficulties can be common in childhood. - your child may grow out of them as s/ he gets older and stronger.	GP. Paediatrician. Ear, nose and throat (ENT) specialist.
0 - 5 years	Sleep apnoea: when the breathing is repeatedly interrupted while sleeping. It is routine for a sleep study to be required before and 3 months after starting Growth Hormone.	Paediatrician. Endocrinologist, Respiratory Team.
0 - 5 years	Scoliosis (curvature of the spine). Best practice for low tone is not to allow the child to sit unaided until full trunk control is achieved. It is routine for a full spine Xray to be taken when the child can go from lying to seated unaided.	Paediatrician. Orthopaedic consultant.

0 - 5 years	An increase in foot, leg and hip alignment issues can be seen with PWS. This can be monitored by the child's medical team and may need corrective actions to be taken, such as ankle supports (SMAFOs).	Paediatrician. Orthopaedic Consultant, Physiotherapist.
0 – 1 year	Slow growth (height, hands and feet). Growth hormone (GH) treatment is prescribed for children with PWS in Ireland. A referral should be made to a paediatric endocrinologist to get the process underway.	Paediatric endocrinologist and endocrine nurses.
0 – 5 years	Specific Dietary Requirements. A balanced wholesome diet with correct portion control is required to ensure your little one stays healthy and avoids excessive weight gain.	Paediatrician. Dietician.
6 mths – 2 years	Delayed and/or disordered speech	Speech therapist

Special health risk features

Babies and children with PWS, whilst having many of the same health issues as other children, do have some special characteristics of which you should make professionals aware. **Not all children with PWS will have these issues, or have these issues to the same degree:**

- High pain threshold. You will get to know your own child's reaction to pain, but if they do not seem to feel pain as much as other children, ensure this fact is made known to those caring for your child.
- Easy bruising. Because of a high pain threshold, children may not be aware of how the bruising came about.
- Poor blood circulation - seems to improve with age in many children.
- Poor body thermostat - may have an unusual response to infection i.e. no raised temperature or, alternatively, a very high temperature. Some children may have little awareness of when they are feeling too hot or cold. It's a good idea to know what your child's baseline temperature is, their temperature when feeling healthy.
- Reaction to anaesthetic. Can be very drowsy after anaesthetic and may be difficult to keep awake for the first day. Some have more severe reactions. Anaesthetist should be aware that the child has PWS. There are leaflets with specific medical information written for Anaesthetists which you can request from PWSAI if your child is due to get an anaesthetic.

Vaccinations

No special risks have been identified for children with PWS with any of the usual childhood

vaccination programmes. Additional vaccines for flu or pneumonia may sometimes be required. Your GP or health visitor will advise which vaccinations are needed and when these should be carried out.

Therapeutic and Medical Services

As described above, medical services are provided by a variety of specialists. Typically babies and children diagnosed with PWS in Ireland are referred to the paediatric endocrinology department in Tallaght hospital. The paediatric endocrinology team will in turn refer your child to other medical services as they are needed - e.g. orthopaedics and respiratory consultants.

The therapeutic and other support services available to children with disabilities in Ireland vary significantly around the country. Children with PWS should be referred to a multidisciplinary service-providers within their own area (Early Intervention Team) **at the time of diagnosis**. Usually, these providers will offer services such as physiotherapy, occupational therapy, speech and language therapy, community nursing and psychology. Specific programmes should be developed for your child. The waiting times for individual services and the extent of the services provided varies significantly. It's a good idea to know when your referral has been made, **and to follow it up** to ensure your child is seen as soon as possible.

Anyone who believes that their child has a disability is entitled to request an assessment of that child's needs. These assessments are carried out by Assessment Officers, who are independent officers of the HSE. After an assessment has been completed a service statement will be drawn up by a HSE liaison officer - this will document what services will be provided to your child. A good description of the Assessment of Needs and Service Statement processes can be found on the Citizens Information website at: http://www.citizensinformation.ie/en/health/health_services_for_people_with_disabilities/assessment_of_need_for_people_with_disabilites.html

Educational Services and Supports

Ireland has a particularly good Access and Inclusion Model (AIMs)

“The Access and Inclusion Model (AIM) is a model of supports designed to ensure that children with disabilities can access the Early Childhood Care and Education (ECCE) Programme” <https://aim.gov.ie/>

When your child gets closer to preschool age, talk to your multidisciplinary coordinator about your child's preschool needs. In most cases children with PWS attend mainstream preschool with additional support in place.

Financial Supports

There are a range of financial supports that may be available to families caring for a child with PWS. An up to date list is available on PWSAI's website.

Want to talk?

If you have a particular query or would like to chat to another parent of a child with PWS please contact us anytime, via Facebook, email info@pwsai.ie or 087 252 2832.