

Awaiting Diagnosis?



Action for disabled & terminally ill children in th UK

Awaiting Diagnosis?

Our aim is to help parents to understand the process of diagnosis and testing, highlighting common feelings and responses, questions and options.

Index

- “They don’t know what’s wrong, so they want to carry out tests- what’s going on?”
- “It can’t be true – I don’t believe it”
- “I am so very angry at what has happened”
- “I feel so guilty – could I have done something?”
- “I can’t think straight – I was so shocked”
- “What types of tests can be done, how and when?”
- “How can I get another point of view?”
- “Is my child just like others?”

“They don’t know what’s wrong and want to do tests - what’s going on?”

For parents of a child suspected of having a disease or disorder, waiting for the results of tests can be agonising. Their fear of the unknown is understandable. However, Doctors and other professionals need time to get results and process the information the tests reveal. Some tests are complex and require time between phases, so there may be some unavoidable delay before the full range of results is available. Those conducting the tests will do all they can, within the constraints of the time taken by the laboratory or department, to develop and interpret results as quickly as possible. It may also take time to arrange a clinic appointment for parents to discuss the outcome with their Doctor.

See ‘Making the Best of your Appointment’

Specialists recommend or arrange tests related to health, development or education, to aid diagnosis or assessment. These tests are designed to confirm

Awaiting Diagnosis?

or rule out certain conditions or to explain physical abnormality, disease, developmental problems or unusual symptoms. Parents need be assured that no unnecessary tests will be carried out. They have the right to ask what the tests are for, why they are being done and what they are likely to reveal, so that they can make more informed choices and decisions.

Parents may deal with this very difficult and emotional period in several different ways. They may experience denial, anger, guilt, shock or a mixture of emotions.

“It can’t be true – I don’t believe it”

The Consultant is most likely to take the responsibility of passing on a diagnosis to the parents, though sometimes the job is delegated to another member of the team. There can be no pleasant way of giving such information and no easy way of receiving it. For parents, the moment is so loaded with emotion that it is difficult to absorb all the facts at once. After the initial shock, some are able to adjust to the situation reasonably quickly (especially if they were already aware that there was a significant problem). For others, however, these feelings may be much harder to deal with.

Denial – Some parents find it impossible to believe that something is wrong with their child. This is quite a common reaction in the early stages but the feeling usually passes once they come to a real understanding of the situation. There are some parents, however, who remain so afraid of the possible outcome that they continue to believe that nothing untoward will be revealed (often despite clear indications to the contrary). They may even refuse to agree to the taking of samples or fail to attend appointments, rather than confront the situation. In some cases, their feelings of denial are so persistent (consciously or subconsciously) that they are reluctant to report important symptoms or changes in behaviour.

Parents in denial may develop an over-optimistic approach because they find it impossible to believe the diagnosis. Family or friends may reinforce such a view, using expressions such as, ‘doctors can make mistakes’ or ‘I’m sure there will be nothing wrong’. This is often their way of showing support, but it can sometimes make acceptance even harder for the parents.

Awaiting Diagnosis?



During this early period after diagnosis, it can be helpful if parents try to adopt a sensible, informed and realistic understanding of the information they have been given. Maintaining a balanced view is not easy but, if it can be achieved, it can provide a breathing space while they adjust to the situation. It also equips them to co-operate fully with their advisors to look at other options, if the initial tests are inconclusive.

Fear of the outcome is perfectly natural, but how can this fear be handled? Most parents feel that it is essential to obtain as much information as possible about the child's condition and to have the opportunity to discuss anything they are anxious about or do not understand. It is very important that the parents' own feelings do not prevent the child receiving the right diagnosis or the best treatment. If they feel that their emotions are getting in the way, they should attempt to reassess their approach and seek as much personal support as they can, in order to move forward. All those involved in the care of the child will understand the parents' fear and confusion and much can be done to support them through this difficult time.

Some parents find it helpful to adopt a thought process that recognises the fear and avoids negative thought, such as 'the doctors must be wrong' and emphasises positive thought, such as 'we will wait to see what the tests reveal and then we will go forward from there'. Working fully with the professionals will ensure that the child receives all the help, treatment and care he/she will need.

"I am so very angry at what has happened"

Anger – If the child's problem can not be identified immediately, worried parents may direct their anger at their Doctor or other healthcare professionals. If there is a delay while samples are collected and the results of tests are confirmed, their anxiety and frustration is intensified.

In some cases, parents may feel resentful towards the person who gives them the diagnosis, because of what they perceive as insensitivity or lack of openness in their attitude.

Awaiting Diagnosis?



The whole situation seems cruel and unfair, prompting such thoughts as 'why me?' The reason for this anger is often difficult to express, leading parents to take out their feelings on the person who, from their viewpoint, has introduced this condition or illness into their lives. It is not an entirely rational emotion but is simply a natural response to a new and frightening situation. Sometimes feelings of anger may be directed towards others, such as a partner or other family member. Imposing negative feelings on others can damage relationships that may be vital to the future welfare of the child.

It is helpful if parents can recognise these feelings and turn them into something more positive, directing them towards a real understanding of the child's problems. It is possible (perhaps with professional help), to harness the anger and channel it into gaining as much useful information as possible about anything that will enhance the child's life, such as support groups, education, aids and equipment, therapies, and so on.

"I feel so guilty – could I have done something?"

Guilt – Everyone wants to do the best for their child. But, there are times when all parents feel that they could have dealt with a situation more quickly, more effectively or in a better way. Many parents of children with special needs feel that they ought to have recognised their child's problems long before they came to the attention of health professionals. Some feel that they might have done more for their child, or handled him/her differently if they had known about the problem earlier. They may even begin to see themselves as poor parents. This is rarely the case; a specific diagnosis can only be made by a medical specialist, using physical examination, observation and a wide range of specialised tests.

If parents are experiencing feelings of guilt, it is important that they talk about them to their Doctor, Health Visitor or Social Worker. The professional will help them to view the situation more clearly and will be able to explain whether or not earlier intervention would have made a significant difference to the outcome.

Awaiting Diagnosis?

“I can’t think straight – I was so shocked”

Panic/Shock – When a parent is told their child has a disorder or disease, it is not at all unusual for them to experience the clinical and/or emotional signs of shock. They feel panicky, confused, emotional and shaky. Panic can colour their views, memories and perceptions of the situation.

In this condition, they may misinterpret information, underestimating or overestimating what they have been told about tests, diagnosis or treatment.

Sometimes these feelings of panic or shock do not show themselves immediately; some parents recall receiving bad news about their child’s condition, leaving the hospital and returning to work, apparently on ‘automatic pilot’. The full implications of the information may only make itself felt after a time. Everyone deals with stress in different ways, according to their personality, temperament and past experiences and there is no correct or incorrect way to feel. Each person copes in the best way they can, until they begin to feel calmer and more able to cope with the situation.

It may seem impossible to cultivate calmness in such a situation but some parents have found it beneficial to write down all the information they have been given, listing details of the facts they definitely recall and those they are not completely sure about. Each piece of information is then given a rating of 1 to 5. A score of 5 is given for those facts they are sure about and 1 to those they are most unsure about, with grades in between. Usually, they find that there are more items with a score of 1 and fewer with a score of 5. This may indicate that some of the information was ‘blotted out’ by the shock of the experience and, now that they feel calmer, they may need to return to the Doctor or professional advisor for further clarification. This list can be used regularly as a reminder.

Where there are uncertainties, it is easy for the imagination to run wild. If possible, parents should try to disregard any information they are not completely sure about and focus on those points about which they are certain. Dwelling on the worst possible aspects of the child’s condition and anticipating the worst outcome is usually an initial panic response to hearing unpleasant news. This is likely to subside with time.

Awaiting Diagnosis?

“What types of tests can be done, how and when?”

Doctors and other professionals must decide which investigations would be most likely to clarify the nature of the condition. They take great care to ensure that any tests which might cause pain, distress or inconvenience are not undertaken unless they are absolutely necessary. When assessing the need for further investigation, the Doctors will always act in the child's best interests.

Many types of clinical tests and other investigations are used to aid diagnosis and may be carried out by a Doctor, specialist or separate department. Sometimes, diagnostic tests are run in conjunction with others, in order to produce a complete picture. Samples may be collected at different times so when several tests need to be carried out in conjunction, there is often a delay before the full range of results is collated.

The main types of tests available include:

The collection and analysis of physical samples of blood, urine, faeces, skin, bodily fluids and tissue. Physical samples are used in the analysis of chemicals, proteins, cell status, infection, genes and chromosomes.

In some cases, samples can be collected by parents and handed over at an outpatient clinic. Others can be collected when the child is in hospital or during a surgical procedure.

The collection and analysis of data from tests on the responses of the brain, nervous system, senses (such as hearing or vision) or organs (such as the heart or kidneys). Tests used to monitor activity and function of certain systems of the body include EEG (electroencephalogram), ECG (electrocardiogram) and audiogram (hearing test). These tests may be carried out at an outpatient appointment, during a stay in hospital or during a surgical procedure.

The creation and analysis of visual images or sound recordings of the structure, shape and function of internal organs of the body, to detect any abnormality. These tests include X-rays (electromagnetic radiation), ultrasound scanning (sound wave scanning), CAT scan (Computed Axial Tomography) and MRI scan (Magnetic Resonance Imaging).

Awaiting Diagnosis?

These tests are carried out during an outpatient appointment or during a stay in hospital. Young children may require an anaesthetic to undergo some tests as it is necessary to lie still for a period of time.

Psychological, educational and psychiatric assessment, using sets of specially designed tests to look at the child's behaviour, responses, learning, development and communication. These tests or assessments are usually carried out at an outpatient appointment, during home visits, at a community clinic or other assessment facility.

“How can I get another point of view?”

Parents who are concerned about the outcome of tests or the diagnosis, may wish to obtain another opinion. Some parents feel that there might be someone, somewhere, who may have different views or improved treatment. Doctors and others involved in the care of the child usually want to work in partnership with the parents and, so long as the parents explain their concerns in a calm and reasonable manner, they will understand and will not be offended by the request for a second opinion. It is usually better to wait for the test results to be finalised before requesting a second opinion, so that all the necessary information is available. This ensures that any new advisor they consult has the opportunity to look at the full range of results. Every effort is made to understand how the parents feel.

There are some hospitals or specialised units that have a particular interest in certain conditions or types of disorders. The professionals dealing with the child may be able to tell parents of any such unit that specialises in their child's problem.

Awaiting Diagnosis?

“Is my child just like others?”

Individuality – In most disorders or syndromes, there are common factors but, even within the same condition, no two children are affected in exactly the same way. Many parents derive great benefit from contact with others who have a child with the same disorder. However, it is important that they bear in mind that their situation will not be identical to that of other families. There is much to be said for mutual support between parents but, in any disorder, the range and severity of symptoms will vary from child to child.

“Will knowing a specific disorder name change how I see/ appreciate/treat my child?”

Most parents say that knowing a named condition helps them. I needed to know, what?, and why?, and, when I found out, I was able to use the information where it was useful, but most of the time I just think of Susie as Susie, not Susie with this syndrome. This is the most common experience of families. They felt the benefit from a diagnosis, but once they have learnt about it and understood and know when and where to use the proper name – they just put it aside and treat the child as they did before, but perhaps with greater insight into why some things are the way they are, and most families report that this helps them cope better.





Newlife Centre
Hemlock Way, Cannock,
Staffordshire WS11 7GF



Tel: 01543 468888/462777



Email: info@newlifecharity.co.uk



www.newlifecharity.co.uk

Registered Charity No. 1001817 Formerly known as Birth Defects Foundation / Newlife Foundation.