Scottish SPINA BIFIDA Association

Adults with Hydrocephalus

For those caring for adults with hydrocephalus

One of a series of fact sheets produced by the Family Support Service

The number of adults diagnosed as having hydrocephalus is increasing with the more sophisticated diagnostic equipment now available. There is also a large group of adults who had hydrocephalus as babies, or in infancy, who have now reached adulthood. Thus, the knowledge of how these people cope with today's hectic, fast-moving world is developing because, for the first time, we are in a position to learn from them directly.

In the past, about two-thirds of people who had hydrocephalus also had spina bifida and many were not aware that hydrocephalus could occur in isolation. The incidence of spina bifida is declining for a variety of reasons but the number of cases of hydrocephalus has not declined. This is, in part, due to very premature babies being kept alive by improved technology but, in some instances, sustaining haemorrhages in the delicate linings of the brain which can lead to the development of hydrocephalus.

The overwhelming majority have the hydrocephalus controlled by an artificial shunting system which, in theory, maintains the intracranial pressure at a normal level. One has to bear in mind that this is a man made device and not as flexible as nature's way of draining and maintaining a normal flow of fluid in and around the brain. However, it saves lives and when functioning well, is most effective.

Many people who have had hydrocephalus (controlled with or without a shunt) will have sustained some impairment of the brain function although they may fall well within the band of the normal intellect and be able to hold down a job, marry, have children etc. However, there are those who require considerable support, encouragement and sensitive understanding in order to lead fulfilling lives in a sheltered environment. It can be quite frustrating and bewildering for staff or family who are offering care and support and it is hoped that the following may offer some insight, plus strategies for coping with this situation.

It may also stimulate some fresh approaches and this is how progress is made.

Slow Thought Processes

There may be delay in answering questions, not because the question is not understood but it is taking a little longer to decode and interpret. By the same token, memory takes longer to be securely recorded and information may have to be repeated and reinforced by asking the person to reflect back and/or by giving written instructions as well as verbal instructions.

It is important to remember to speak steadily, simply and clearly. Present one item at a time and avoid overloading with too many instructions, for instance 'Time for lunch", pause for the idea to register, then 'Clear away or tidy office desk (or work bench)'. When this has been done, 'Go to the dining room'. To give all three directions in one breath may result in only the last part producing a response because it is the last thing heard or they may just sit and look at the person talking, with no physical reaction.

If there is evidence of poor memory, it is helpful to ask them to repeat any instructions. This spotlights any faults and, by repetition, enables the instructions to be more securely established in the memory bank. Often directions have to be repeated several times but try to avoid any sign of impatience. If an errand or task is the issue, try writing the keywords in the correct sequence as a memory jogger. The young adult will be trying quite hard to remember and can easily be put off or feel that they are likely to fail, so a touch of humour may help.

Eagerness to please and agree

Although this is a positive attitude, frequently seen with this disability, it can occasionally lead to incorrect decisions being made. Whoever is in the company of the young person is 'the man of the moment' and there is a desire to comply with any suggestions made. An example of how far-reaching this can be is illustrated by the case of a young married couple (the wife had hydrocephalus). When visiting her parents, the couple were advised to have a divorce, as the parents did not think their daughter could cope with married life, and she was persuaded to agree. However, when the couple returned home and discussed the situation together, she had no desire to divorce and had a happy marriage. Until it was realised that her ambivalence

was influenced by the effects of hydrocephalus, a bewildering picture was emerging. Decision-making is very difficult for some and remains so.

The *here and now* is reality but the future is a difficult concept. In other words, they can deal with the present but cannot really forecast or reflect retrospectively. This is another reason why immediate decisions may be made which are not in their best interest or what they truly wish.

This desire to please leads some young people to admit to saying they can do something or know something, when they really cannot and do not. They may tell an apparent truth when everyone, including themselves, know that this is false. It is almost as if they are following a format of perceived good behaviour and cannot deviate from this.

It is important to show no impatience but to talk the situation through with them, sensitively and carefully, pointing out where they may be giving the incorrect reply. They may be disarmingly frank once the truth is acknowledged and this makes it easier to work with them and solve the dilemma. A challenging attitude is likely to produce confusion or anger and any further progress comes to a halt.

Poor organisational skills

This problem can make life hard for them and probably revolves around several deficits, eg, poor memory, poor sequencing abilities. A structured routine is required to give confidence and order to their lives. Discreet overseeing and, occasionally, more concrete support is required, even for the most able, because their abilities fluctuate from day to day. For this reason, it is important not to make snap judgements on abilities but to observe over a period of time in order to gain a truer picture.

Patience is the keyword for dealing with many of the problems encountered and especially where forward planning is concerned, involving coming to decisions or organising how to deal with certain practical issues around increasing independence. This calls into play memory, sequencing, imagining (or conceptualising), and reasoning, all of which may be skills they lack. Young people often require to talk through problems or plans for the future, over and over again, to establish them securely and to come to terms with the reasoning behind them.

Structured routines, written checklists, agreed programmes, are all tried and proven methods of encouraging independence and security. Occasionally it is felt by some that too much structure is demeaning but if the need for this is carefully explained (and similarities are made with diaries, shopping lists, recipes which everyone uses) this may give the young person licence to accept this way of life.

A further technique is to use the recorded voice. This has been tried using the carer's voice to give direction and the young person playing the relevant section as a reminder and to keep them on task. An even stronger stimulus is for the young person themselves to make a recording, giving themselves positive reminders of what the next steps might be. This can be an enjoyable project to work on and can be altered or added to as the situation changes. This also means that, once the tape has been made, the young person is able to work alone which helps to increase their self-confidence. The tape can be played on a Walkman, thus ensuring privacy and increasing the effects of the instructions.

Even with all these measures, a few will still require a vocal prompt from someone on the spot to provoke them into doing a task.

It is always better to give a brief direct command rather than attempt to use long explanations or sarcasm, which will be entirely lost and unlikely to have the desired effect, eg. Someone day-dreaming at the meal table and not eating may need to be told to 'pick up your spoon, now eat' and that is enough for them to initiate the action. Saying things like 'Are you waiting for Christmas?' or 'Don't just sit there' although tempting, no doubt, are likely to be counter-productive. Why are you suddenly talking about Christmas-what is the connection? If they pick up on the latter part of the sentence 'Sit there!' then that is alright because that is just what they are doing.

Difficulty with understanding (receptive language problems).

Any statements made to the young person have to be clear and unambiguous as there is a tendency to take things at face value. It may be necessary to check that the meaning of words have been well understood because, despite a good flow of speech on their part, these may be phrases learned from the past, used by those with whom they are living, heard on TV etc and not necessarily original thought with the relevant understanding.

Sometimes it helps to rephrase a sentence but always keep it clear and simple and try not to be ambiguous because there is a danger that they will take statements very literally. Some of the adults will tell you this themselves. Instructions or messages must be precise, eg.' Will these dirty clothes go into the laundry basket?' may produce the answer 'No' because the clothes will not go there by themselves. But, if 'Is there room for these dirty clothes in the laundry basket?' were said, the answer could be 'Yes'.

Dislike of Change

Change can provoke considerable distress for some and, for a while, they may lose their ability to think clearly. Certainly, a change of environment will take some time for adjustment and for serenity to return. In these circumstances extra support and the opportunity to talk the matter through should be available and plenty of time allowed for settling in.

Patience and possibly some retraining may be needed when changes occur, i.e. a change of room, alteration in the position of the furniture, new staff, a new home etc.

Many skills may appear to have been lost for a while and certainly the young person may show signs of anxiety and bewilderment. With a sensitive approach and increased support, their former skills will re-emerge but it may take time. Pressure to hurry or progress more rapidly will only delay them because they cannot cope with this attitude. It really stops them being able to think. Again this has been learned from our increasing group of articulate adults.

Just giving the young person time to talk through some of their anxieties and listening attentively is of great value because it acknowledges the situation and gives dignity to their opinions. Many are very proud young people and so eager to appear in control while at the same time, deep down, being aware that there are underlying problems.

Summary

Despite all of these underlying, unseen traits, the majority of people with hydrocephalus are pleasant and sociable. Each person is different and it takes time to really know them. The degree to which the hydrocephalus has affected the person varies enormously, from hardly at all to quite severely-but it is important, where programmes, decisions or life changes are being contemplated, to take into consideration the hidden effect of the hydrocephalus. This particularly applies in residential situations or when drawing up and implementing care plans in the community.

There are two key issues to remember:

Adequate, sensitive support

Make sure that the pace is right and avoid:

PRESSURE

If you have any questions or would like further information, please do not hesitate to contact the Family Support Workers at:

Scottish Spina Bifida Association - Family Support Service

Address: The Dan Young Building, 6 Craighalbert Way, Cumbernauld, G68 0LS • Tel: 01236 794516 • Fax: 01236 736435

Lo-Call Helpline: 08459 11 11 12 • E-mail: familysupport@ssba.org.uk • Web: www.ssba.org.uk