# "In Our Own Words" -
# Dysphasic People
# Talking

Compiled by
Members of the
CITY DYSPHASIC GROUP

and

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## Contents

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# "IN OUR OWN WORDS" - DYSPHASIC PEOPLE TALKING

## PREFACE BY JEAN KERR MCST

Speech Therapist, City Dysphasic Group

This booklet was produced by some members of the City Dysphasic Group (CDG). The CDG (formerly the Blackfriars Dysphasic Group) was set up in 1970 to provide intensive therapy for people suffering from dysphasia (speech and language problems) following a stroke or other form of brain damage. The group members are all dysphasic.

Many of those who compiled this booklet were completely without speech initially; all still have difficulties with speech, reading, writing and understanding spoken words. With the exception of the medical section, which they asked me to write, and a supplementary section on the role of the speech therapist, the words are their own. It is a remarkable achievement.

Group members are of varying ages and backgrounds, yet what is striking is the unanimity of feelings and opinions expressed. Thus, while they would make no claim to this effect, the booklet may be said to speak for all dysphasic people - maybe all stroke victims. Some of the feelings expressed are upsetting, some alarming in the despair they convey. Yet the booklet is important precisely because it has allowed group members to voice feelings that, for a variety of reasons, dysphasic people are often unable to express. This may be because they do not have the words, or because they are frightened, or because those around them do not allow them to talk about their grief.

Producing the booklet brought them together, encouraged them to share experiences and support one another. It is a testament to the therapeutic power of groups, and to their courage in adjusting to their problems.

# INTRODUCTION

By Members of the
CITY DYSPHASIC GROUP

We decided to produce this booklet about the effect of a stroke and being dysphasic for the following reasons:

1. To let other stroke victims know that they are not alone;

2. To help family and friends understand the difficulties;

3. To remind other group members and stroke victims of the improvements that have been made and can be made;

4. To learn from the experiences of one another;

5. To inform all those who work with stroke victims;

6. To inform the public;

7. To encourage discussion amongst ourselves;

We have covered the many and varied aspects of stroke and dysphasia in separate sections, but there are lots of overlaps.

We have had some help in writing down our ideas, but the words are our own.

## Medical Aspects

A stroke happens when there is an interruption in the blood supply to the brain. This may be because a clot blocks a blood vessel, or because a vessel bursts, allowing blood to escape. The area of brain supplied by that vessel is damaged because it is deprived of blood and therefore oxygen. If a vessel has burst, the blood that has escaped may cause damage by irritating brain tissue or forming a clot.

Strokes are so called because they normally happen suddenly. They have many other names, according to their various effects e.g. cerebral haemorrhage, cerebral infarct, cerebral thrombosis, apoplexy, aneurysm or cerebrovascular accident (CVA). Although usually thought of as something that afflicts the old, strokes can happen to young people; at the CDG there are 10 members under the age of 40.

The results depend on the area of the brain that has been damaged and how much damage has been done. People may have a variety of problems following a stroke, such as paralysis or speech difficulties.

## Dysphasia

The language centre is situated on the left side of the brain in most people. If this area is damaged the result is dysphasia, (problems with language). People with dysphasia may have difficulties in any or all of the following areas: finding the right words to express themselves, speaking, understanding what they read, understanding the spoken word, or writing. The severity and exact type and mix of problems depends on the area that has been damaged, and other factors unique to each person.

All members of the CDG are dysphasic and, while they may have many problems in common, the exact form these problems take varies from person to person. Those who produced this booklet have problems which are now mild in some ways, but still significant.

## "At the Beginning . .

The beginning may last for days, weeks or even months. This time is often harder for the family than the stroke victim, because you are too ill or confused to know what is happening. The family experience fear. The immediate fear is that you will die, but as you recover, the effects of the stroke emerge. It takes a while to accept these, and they may be frightening.

After a stroke, most people are confused and many are unresponsive and blank. None of us understood what had happened or the implications. Some people did not recognise their family or could not remember their names. Almost all of us could not talk at all and most had problems understanding what people said to us. Some of us talked a lot, but did not realise we were not making sense, some of us thought we'd gone deaf. The first words were often swear words. Some of us were paralysed in the right arm and leg, or had pain or tingling or numbness. All of us felt tired all the time. We slept a lot.

The feelings of frustration were overwhelming. Sometimes these led to angry outbursts, or complete withdrawal. We found noises too loud, lights too bright, everything too tiring. We were irritable, sometimes even aggressive.

As we became more aware, we still didn't understand. We found it hard to cope with all the things we could not do, but believed that everything would be all right in a short while. This feeling sometimes continued for a year or longer. Most of us hoped and believed we could be back to normal very soon. Our families often believed this too.

Gradually, we began to recognise how the stroke had affected us. Then came depression, with feelings of helplessness, hopelessness and tears. We responded in exaggerated ways and felt that we'd lost control.

## Emotions

The way we felt was the most important thing after the stroke. Speech and movement were important too, but what we needed to understand was our emotions. We needed to talk.

As we became more aware, most of us felt we wanted to die.

At the beginning most of us felt unhappy but we were not always sure why. Some of us cried openly, often and for a long time. We were unable to comfort those close to us who were also confused and unhappy. We didn't want to talk about what had happened. We were scared and afraid that people might think we were stupid. It was a great relief to meet others who had experienced the same thing, to talk, be understood, be supported and liked.

Emotions are exaggerated. Feelings are felt more keenly. Having a stroke is shattering. It is difficult to explain how great the loss is. There is a feeling of helplessness and losing control. This comes and goes.

We are learning to accept this, but we often feel angry and depressed.

## Family

Some people do not have families. Some have wives or husbands, boyfriends or girlfriends. Some have young children, others children who are grown-up.

Relationships are always changed after a stroke. Over time, this may be for better or worse. It is never good at the beginning. It is important for people to understand that these changes happen. Some families grow closer, some simply cannot cope with the changes and strains. As time goes by, you learn. You become more mature, you learn about yourselves and become more tolerant. Families can still become exasperated. Even though they begin to understand, they have their own feelings to cope with. They are unhappy too. Sometimes they may say "Don't give me all that stroke stuff again!"

## Friends

Friends may be uncomfortable or embarrassed by what has happened, because they don't know how to help. They don't understand. Sometimes they are frightened as if they realise this may happen to them. To start with they are caring, but gradually they may drift away. Some stick by you.

## Friends ... continued

You learn who your real friends are and sometimes make new friends.

Some people have no friends, through choice or circumstance. They find things hard because they need to talk and need help, but they have nobody to ask.

## Finance

A stroke stops you working, sometimes for a long time, sometimes for ever. This brings a devastating drop in income. Even if you were not working before, it is appalling. We would like to be able to provide for ourselves and our families, but we can't.

It is important to contact a social worker to make sure you are getting your benefits. You are entitled to these.

If you know someone who has had a stroke, do check that someone is sorting out their finances.

## Work

Most of us do not go back to work after a stroke, at least not for a long time. It is hard to accept that you may not go back to your old job or work again. It brings financial problems and you lose confidence. Even if you were unemployed before your stroke, it is worse because your choices are even more limited.

## Loss of Independence

Doing things on our own has become more difficult, demanding or impossible. In helping ourselves, everything takes much longer to do. People can be overprotective and stop us doing things alone because they care and worry about us. It may be they don't believe we can do some things alone, or that it will take too long. They don't allow us to do things on our own and they don't ask us what we want. It is important to do things on your own albeit imperfectly.

## Loss of Independence ... continued

Most of us find it hard to tell other people we've had a stroke. We don't want to ask for help and we don't want pity. However, some of us have found it helps to tell people. Then they are more understanding and give us more time. You shouldn't go on about it though!

Giving up previous responsibilities is hard to accept. Family and friends have taken on many of these but we feel useless. Jobs are gone, our confidence has gone and we feel dependent. Everyone needs to feel needed and that they can do something. We feel limited.

## Leisure

We all have time on our hands, but because of the stroke, old hobbies and interests may be impossible. You have to look for new ways to spend your time. Some of these may be things you have never considered before. Have a go.

## The Future

Who knows? As time goes by, we are able to look to the future with more certainty and less despair.

It is important to keep battling. It is a long slow grind, but you have to keep going. You will make progress. You need goals, but they must be realistic and they need to change as time goes by. You must be pragmatic and practical.

Accepting reality takes time and is painful. Sometimes family and friends don't want you to talk about it, because they need to believe everything will be all right. Remember, there are other people worse off than you. It helps a bit to meet other people who have experienced the same thing. It is important not to expect too much too soon. We still feel low sometimes. When we have a low time, it is hard to keep realistic without giving in to despair. We still feel overwhelmed by a desire for things to be as they were before. But each time we feel low, it is not quite as low as before. You have to believe, bad as it is, you will never feel quite so bad again. It is important to acknowledge your feelings and be

## The Future .. . continued

truthful. You will learn to cope with feelings of loss and uncertainty and be realistic. Most of us believe we were realistic right from the start, but when others say we are more realistic, that's when its true.

We have lost the future we always assumed we would have. Our dreams of the future are at an end. It is hard to let go of these dreams, but we must. That is part of making progress.

The future is not months or years ahead, it is tomorrow or next week. We are learning to face things a day at a time. We are learning that we can help each other.

## The Role of the Speech Therapist

When someone becomes dysphasic, the speech therapist has an obvious role in assessing the exact type and severity of the problems and carrying out appropriate treatment.

In addition, they are able to explain the nature of the difficulties to the person who is. affected, to his or her family, and to staff working with them, such as doctors, nurses and physiotherapists. This also involves stating what the problem is not, for example, that it is not a loss of memory or intelligence and giving information about the probable rate and extent of recovery. The therapist may also suggest immediate practical ways of encouraging communication and overcoming difficulties. In this way progress is stimulated and misunderstandings and confusion may be avoided.

Just as important, however, is the role of the speech therapist as counsellor. One of the most striking aspects of all that the group has written is that most of it refers to feelings - of confusion, of anger and of despair. These feelings are inevitable after something as catastrophic as a stroke. They form part of the bereavement reaction that follows all major illness, especially if it brings with it long-term handicap. Despite this, these feelings frequently take people by surprise, because of their strength and the way they last. Just as in bereavement, there are several stages; shock and denial, anger, depression, then acceptance and adjustment. If recovery is to be complete, these stages must be worked through.

Even if the handicaps are apparently small and progress is good, people suffer while they come to terms with what has happened to them, as do their families. Facing the losses, such as loss of health, loss of abilities, loss of the future one assumed one would have, is a painful and lengthy process.

The presence of the speech therapist is important precisely because it highlights and validates the need to communicate. Counselling may take many forms, but at its heart it gives the person and their family time and the opportunity and permission to express their feelings and show that they are acceptable even if they are strong and upsetting. People suffer a devastating loss of confidence and self-esteem because they are no longer what they were before. By giving time the therapist shows that this person is worthy of time and attention, that they are important.

The aim is to provide the space and support to allow people to acknowledge what they have lost, to find different ways of seeing themselves and their problems and different ways of responding. They are encouraged to show their feelings even if they seem "wrong", to begin taking control of themselves and what happens to them. In this way, they can begin to feel effective and worthwhile again.

For people who are dysphasic, this process is especially hard because of their communication problems. They need not only additional time, but the help of someone who understands their difficulties and can help overcome them. While many people seem to have natural intuitive skills to help someone in need, the speech therapist is in a unique position to be able to do this for people with dysphasia and for their families.

Jean Kerr and Group Members

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ACTION FOR DYSPHASIC ADULTS works for improved care and rehabilitation for adults who have lost some, or all of their ability to use speech and language as a result of stroke, head injury or other neurological damage. ADA is the only organisation exclusively concerned to help dysphasic people and their carers. Services include:-

- The provision of advice and information to dysphasic people and their families

- The production and distribution of an extensive range of publications and training materials

- The operation of a membership scheme

- Study days and lectures

- Providing start-up grants for new local branches and support groups throughout the country

- Encouraging research into dysphasia and new methods of treatment

- Bringing to the public's attention the problems facing dysphasic people and those who care for them.

If you wish to know more about ADA's work and publications, or if you are in need of advice and guidance, we will be pleased to hear from you.

ADA's booklets are free to all dysphasic people and their families, but any contribution towards our costs, however small, will be gratefully received.

# THE CITY DYSPHASIC GROUP

The Centre for Clinical & Communication Studies
The City University, Walmsley House, St. John Street,
London EC1

The City Dysphasic Group is a charitably funded speech therapy clinic based in the Department of Clinical Communication at City University. It provides intensive long-term treatment for people suffering from dysphasia following a stroke or some other form of brain damage.

Group members attend two or three days a week for treatment in large and small groups and on an individual basis. The groups are run by speech therapists and supervised speech therapy students, and there is also a self-help group run by therapists and volunteers.

Group members are from all over London and beyond, and benefit not only from the therapy on offer, but also the opportunity to meet others and the mutual support this generates.

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