

CARERS

an
**ESSENTIAL
GUIDE
to
CARERS *of*
HEART PATIENTS**

Includes:

the impact and effects of heart disease, and the support and information available

Suffolk
HImP



Introduction

This booklet has been compiled to help carers to understand some of the problems and behaviour that they may have to face, and endure, from the person or loved one who has suddenly suffered a heart condition, (normally a heart attack or angina). It will also assist and help the carer to come to terms with their own emotions and worries that occurs with sudden shock and of further changes that may occur.

It is hoped that by informing carers at a very early stage about the problems, and worries that can occur, and the help available, they will be better informed and better prepared to plan for the long term effect in a positive manner.

This booklet is the result of experiences encountered by carers and people with heart disease. It is set out into headings with a brief outline on each ~ ranging from hospitalisation, getting back to normal (rehabilitation), and the professional and voluntary support available.

It must be noted that in no way does this booklet profess to provide all the detailed information about caring for someone with heart disease, but it does offer a wide range of practical information, experiences of individuals who have had heart disease, services and the support available.

TABLE of CONTENTS

2	INTRODUCTION
3	THE IMPACT AND EFFECTS
5	RISK FACTORS
8	REHABILITATION
10	HEALTHY EATING
11	EXERCISE
12	SUPPORT AND INFORMATION
14	ACTUAL EXPERIENCES
19	CONCLUSION

THE IMPACT AND EFFECTS

Angina and heart attacks are common and can cause great alarm and anxiety. An attack is a most frightening experience, not only to the person, but to their carers, family, and friends.

It is natural to wonder what caused the attack. It can happen at any time, day, or night and can develop when exercising, working, or resting. It can also be brought on by intense physical and emotional stress which is part of our life style. It is a condition, that has an impact on all the family including personal relationships and employment .

As a carer experiences the changes that occur, problems that were once insignificant mount up, the carer may feel depressed, or lonely. They may ask the question, "Why did it happen to us?" Being aware of the facts will help alleviate the worry, and consequently reduce the depression.

Encouragement, support, and understanding, combined with the right guidance can make all the difference to the recovery of the person being cared for and will make the situation all the more tenable for everyone involved.



In order for the patient to get back to a normal way of life, there may be a need to re-adjust and make certain modifications to their life style, such as 'stopping smoking', 'developing and sustaining a reasonable healthy diet', and 'taking a regular programme of exercise'. These changes should include the carer and members of the family in order to make sure of the very best possible recovery and help reduce any further risk of a another heart, or angina attack.

As a carer, it is important to realise that caring for someone at home is time consuming and a responsibility for which help, information, and support may be needed.

*(See the section on **SUPPORT AND INFORMATION**)*

When the attack occurs a carer may experience shock, depression, and loneliness, as well as the worry of seeing a loved one not only suffering from pain but also the agony of having to accept that they have suffered a heart attack. It is important to realise that the lives of those affected have changed but not finished.

This can be illustrated by assuming that the person has been shunted from the 'main, fast line of life' on to a 'slow branch line' where they have to watch the signals and travel slowly. They will need help and encouragement along the way, meeting different people and joining in with rehabilitation. Eventually they will see a light at the end of the tunnel, emerging and arriving at the station where they will be given the green signal to rejoin the main line and carry on their journey.

Can it happen again? In general terms, someone who has had a heart attack is at above average risk of suffering another attack. This can be substantially reduced by adopting a healthy lifestyle; such as reducing stress, giving up smoking, adopting a healthy diet, exercising regularly and taking the appropriate medicines as prescribed.

Remember that the heart is one of the toughest muscles in the body. A reasonable amount of hard work will not harm it, or cause another attack.

The carer will experience a different kind of trauma, but one which is no less severe. They may undergo and be subjected to periods of mood swings, depression, along with ups and downs which are not easily understood.

Due to worry and their state of mind they do not always absorb all the information which is given. It is only after the person has been discharged from hospital that things really become clearer and the questions start to evolve. It is important that before discharge the carer has received and understood all the relevant information on medicines, appointments, details of rehabilitation



programmes. If in doubt the carer should ask at the hospital, or ask members of a support group.

There are no hard and fast rules that a carer can follow. Everyone has different needs and capabilities. A carer's main task is to be there to encourage the person to do the things that they need to do and are able to accomplish, but at the same time making sure that they do not try, or attempt anything that may be too energetic.

Do not wrap the person in cotton wool, but give them encouragement by setting small targets - be positive and do not overpower them.

It often helps to talk to someone, remember, a problem shared is a problem halved!!

Finally, all being well, the person has survived and you will too. Take every day as a BONUS.

RISK FACTORS

This section outlines some of the risks associated with coronary heart disease. Coronary heart disease is caused by a combination of factors such as smoking, lack of exercise, high blood pressure, high fat diet, circulatory problems and family history of heart disease.

Smoking

In general people who smoke have twice the risk of a heart attack as people who do not. The more you smoke the greater the risk. There is no quick and easy way of stopping, and nothing can make you, it is up to you to want to stop.

Carers and members of the family should also be encouraged to avoid smoking around the person



recovering from an attack because of the dangers associated with passive smoking.

There are many products and therapies to help you stop, it is best to consult your G.P.

Blood Cholesterol Levels

Cholesterol is a fatty substance made in the body by the liver and plays a vital role in the functioning of every cell wall throughout the body. Excess cholesterol levels in the blood stream forms a thin layer on the walls of arteries, which over a long period will reduce the blood flow to the heart muscle increasing the risk of coronary heart disease.

Measuring blood cholesterol level involves the taking of a simple blood sample. The sample is then sent to a laboratory for analysis, depending on the results obtained, a course of treatment may be prescribed by the doctor, or General Practitioner (normally a diet and/or drugs). It may take months to establish control of the blood cholesterol level.



High Blood Pressure

High blood pressure increases the risk of a heart attack if untreated over a period of time, it can cause the heart muscle to become less efficient.

Blood pressure can increase if you are overweight, if there is too much salt intake in your diet, and with too high an intake of alcohol. To control blood pressure; maintain your correct weight, cut down on your salt intake, and by taking on physical activities such as walking, swimming, or cycling. *(See the sections headed **HEALTHY EATING AND EXERCISE**).* Your GP may prescribe drugs to reduce high blood pressure gradually over several weeks, or months.

Overweight (Obese)

It is important to maintain your weight within the recommended range. Carrying excess body weight increases the work of the heart and is associated with high blood pressure and high cholesterol levels. There are no miracle cures, the only way to lose weight is a change eating habits, regular exercise. If you are overweight your G.P. may refer you to a specialist for help.

Stress

While there is no real medical evidence to show that stress causes heart disease, but many doctors believe it can contribute in some way. Stress is part of everyday life and everyone requires some level of stress to function, but too much stress is not good for any one.



There is no easy way of beating stress but relaxation can reduce the effect, taking a walk, reading a book, listening to music, and talking through your problems with someone else can all be helpful. You may also benefit from joining a support group

If you need any more information on the above please consult with the doctor (or nurse) at the hospital, or your General Practitioner after discharge.



REHABILITATION

The aim of rehabilitation is to promote the patients recovery and restore them to as full a life as possible.

Activity is the essential component of rehabilitation; it helps fight coronary heart disease, even in those who have already experienced a heart attack. The heart is a muscle which requires some form of activity, if it is not worked it will tend to get weaker rather than stronger, just the recipe towards another heart attack.

There is no short cut to recovery; it requires effort, commitment, and time. The speed at which people respond to exercise varies enormously, some improve very slowly and so keep working at it. The benefits and rewards are very worthwhile, it will help restore the patient's confidence, assist in the recovery, and improve the quality of life; not only for themselves but also for the carer.

Subject to an initial assessment while hospitalised, the person may be invited to attend the hospital 'cardiac rehabilitation programme', normally starting within four to six weeks after the heart attack. The programme usually involves the person attending up to two afternoons a week over a six to eight week period and is usually run by the Physiotherapy Department. The programme covers three main areas: -

Controlled Exercise; (Tailored to meet the individual's needs).

Relaxation;

Information; (Lectures and discussions given by practical people who are experts in their field. Subjects covered will include lifestyle, diet, treatment, support, etc.,

It is strongly recommended and encouraged that the carers, relatives, or friends (one person per patient) attend these sessions with the patient. This helps lessen the fears and gives the carer a chance to ask questions.

There is a growing number of rehabilitation services that take place in the home soon after discharge. A cardiac nurse will visit the home of the patient to discuss the patient's recovery and activity levels. To find out if one is operating in your area; ask the Ward Nurse before the patient is discharged.

If the patient has not been invited, or is unable to attend the rehabilitation programme for any reason, they may at some time be able to join a local exercise group at a leisure centre, college, community hall, or even use a moderate exercise video/manual in their own home.

NOTE. It is absolutely vital that if the person recovering from an attack decides to undertake one of these type of programmes outside the control and supervision of the hospital or medical staff, that they consult and seek advice from their General Practitioner before attempting to participate.



HEALTHY EATING

Eating a poor diet has been linked to a whole range of illness, in particular heart disease. It is never too late to change your eating habits which may make a difference to your health.

Eating should be pleasurable and fun, but it is important that it is a sensible and balanced diet. Listed below are a few recommendations given by many professional people and organisations including the British Heart Foundation.

- Eat 'five' portions of fruit and vegetables a day.
- Reduce your sugar intake.
- Eat less fat, grill and bake foods. If you have to fry then use vegetable oils such as rapeseed or sunflower.
- Choose lean meats, such as poultry and fish.
- Use low fat cheese, skimmed, or semi-skimmed milk, and margarine high in polyunsaturated fat.
- Eat more fibre i.e. wholegrain bread, cereals, rice, pasta, baked beans, potatoes and pulses.
- Reduce your salt intake, use herbs instead to add flavour.

Dieting can be confusing, do not give up! Choose the right type of diet.

Leaflets on a guide to food labelling, as found on tins and packets can be obtained from most of the major supermarkets and the British Heart Foundation. These leaflets may help you to decipher from the label, what the contents actually contain. Happy hunting!



EXERCISE

Regular exercise has positive benefits for your health, It helps to improve the circulation, lower blood pressure and makes you fitter.

Before starting any major activity programme, it is best to check and discuss the content with your G.P, or rehabilitation nurse who will advise the person (and carer) on the amount and type of exercise best suited to the patient's condition.

At first the person may feel nervous about exercising, which is only natural. Encouragement can be given if the carer, or member of the family accompanies or participates in the activity.

Initially, exercise should be gentle and will gradually increase as the person becomes more stronger, and gains confidence. The best type of exercise are the ones where oxygen is continually replaced as it is used, such as walking, swimming, exercising to music, and cycling. They all involve rhythmic movement and help develop stamina.

Walking is probably the best activity for most people. Start with a comfortable distance and try and increase it a little each week. Wear comfortable supporting shoes and walk on a even surface.


Swimming is an excellent way of exercising because your weight is supported by the water, this allows you to move freely and helps breathing control and stamina. Swimming can be a tiring activity, so it is wise to start with a limited time in the water and build up gradually






SUPPORT AND INFORMATION


Heart Support Groups




While in hospital or during the rehabilitation programme, the patient may be given some information and advice about the local Heart Support Group. These groups are in the main run by people who have experienced, or are suffering from heart disease. Their aim is to promote the welfare and care of heart patients and their partners, and provide social and personal contact with people who share and understand their needs and problems.



The groups normally meet monthly in a social atmosphere. Speakers are invited to give talks on various general subjects. Many groups hold exercise, swimming, and walking sessions not only for the patient but also for the partner/carer. Social functions and outings are arranged along with fund raising events.




While these groups are totally independent and many have charitable status in their own right, the majority are affiliated to the British Heart Foundation. Membership is FREE! - so why not make contact just fill in a membership form, you have nothing to lose, but maybe everything to gain.



British Cardiac Patients Association (Zipper Club), is a support group for people who are to have, or have undergone, heart surgery. They also meet monthly, some members also belong to a heart support group, which is welcomed by both associations.

Support Groups & Community Contacts



HEARTBEAT (East Suffolk)	
Helpline:-	01771 2322355
Helpline Pager:-	01893 352724
Carers Chatline:-	01206 393292
HEARTCARE (Gt. Yarmouth & Waveney)	
Contact:-	01493 780257
Listening Ear:-	01493 667911

UPBEAT (West Suffolk)	
Contact:-	01284 703617
BRITISH CARDIAC PATIENTS ASSOCIATION (Zipper Club):-	01954 202022

Hospitals

IPSWICH HOSPITAL. NHS TRUST:-	01473 712233
PHYSIOTHERAPY SOUTH GYMNASIUM (Cardiac Rehabilitation)	01473 702073
JAMES PAGET HOSPITAL. NHS TRUST:-	01493 452452
Coronary Care Unit Help Line:-	01493 453198
WEST SUFFOLK HOSPITAL. NHS TRUST: -	01284 713000
Cardiac Advisor:-	01284 713611

Agencies, Advice & Welfare

BRITISH HEART FOUNDATION:-	01719 350185
Regional Office:-	01763 242414
Area Organiser:-	01263 720136
(The BHF offer many publications, videos, etc. on heart disease)	
COMMUNITY CARDIAC REHABILITATION. Chantry Clinic, Ipswich	
Contact:-	01473 686371
CITIZEN ADVICE BUREAU 19 Tower St, Ipswich:-	01473 219777
DISABLED ADVICE BUREAU 19 Tower St, Ipswich:-	01473 217313
SUFFOLK CARERS :- 52 Chevalier St, Ipswich	01473 408030
SUFFOK HEALTH INFORMATION CENTRE:-	01473 323446
Free Phone:-	0800 665544
SUFFOLK HEALTH PROMOTION SERVICE Telephone:-	01473 323543

ACTUAL EXPERIENCES

This section covers actual experiences encountered by carers, who are members of Heart Support Groups.

1. On Holiday

We found out the hard way that having a heart attack is a very frightening experience, not only for the person suffering the attack, but also for the spouse and family who saw a loved one suffering excruciating chest pains. Being away from home on holiday added to the worry and stress of the situation.

After spending fifteen days in hospital, we returned home. We received no after-care, only visits from the G.P. but only after we called for his attendance. We did not know who to turn to for advice or guidance as to what to expect, or what the future may hold.

While the patient is suffering, especially in the early stages, there is a great deal of stress on the carer caused by not knowing at times how to cope. There is a very fine line between being on hand to give help and support when needed, and falling in the trap of being over-protective and not allowing the patient their own space.



Toleration is needed on both sides. It is perhaps easier to walk away when you feel the need to scream and vent your feelings. Yet you need to be there, to comfort when a shoulder is needed to cry on, as this can be an emotional time for both parties.

Very often a patient is reluctant to let the carer know when they are in pain or feeling ill as they do not want to worry their partner. It can be far more worrying to look after a person who never makes a fuss, as you have to be more alert in watching for tell tale signs of stress and discomfort.

It is a great help, and very important for the patient to confide in his partner when he has days of depression or not feeling well. An understanding develops of when the patient wants to be left alone, to rest, or needs to talk to someone. The carer is then aware of the situation and can act accordingly, or be prepared to seek medical advice if necessary.

Fortunately, these days much more help is available in assisting the patient and carer to come to terms after a heart attack. Many support groups have been set up and it is a great help to join a community of fellow colleagues who share the same problems.

The feeling of being so alone to face such a traumatic situation was a dilemma in which I found myself. I had no one to give me any direction or information; what to do, what to expect, or even where to seek any aftercare. Support groups have wonderful facilities and projects where much information can be obtained to assist both patient and carer, and a chance to share experiences with other members.

There can be no definite "do's or don'ts" as each person has different needs. By following sensible guidelines you can look forward to a reasonably new healthy lifestyle and a new-found outlook.



2. Comforting Hints for Carers

When it happens don't panic-even if you feel sick with worry. The ambulance is on its way so talk reassuringly to the patient and make him/her as comfortable as possible. Pack a bag if you can find one!!

At the Hospital

Once in the cardiac ward, the caring, optimistic nursing staff will make you feel more confident. When visiting, smile, smile, smile and talk about coming home - that the house and garden are OK, the pets are being looked after, and you are coping!!

You will find that all the patients are amazingly cheerful and tend to look out for each other. Insist on going to rehabilitation if possible and contact a Heart Support Group for help.

Home Again

Sleep comes eventually. Listening to your partner's breathing can take its toll, but before long you will find you are able to fall asleep before the dawn chorus commences.

"Don't fuss" and "Don't hover" will become very familiar phrases. Take note as it is all part of the recovery process. You, the carer will sometimes be asked to go out for a while so that the patient can get some peace!!

Calorie counting becomes a favourite hobby! Every packet, jar, and label is scrutinised. Don't worry, it does pass, just serve up interesting "healthy" dishes and smile!!

Out and About

The first short walk can be traumatic, but if you talk encouragingly as you walk, taking your time, confidence soon grows and the fresh air does you both good.



3. The Long Journey

The way in which I became a carer to a heart attack patient was slightly different to most, although I am sure it was not unique. My husband had no warning, as is so often the case, but what made it different was the fact that having been admitted to hospital for a heart attack, he did not go home until he had undergone multiple (5) by-pass surgery. Whilst he was in hospital I went through all sorts of emotions:

First denial: *'It's not possible, he has not shown any symptoms'*.

Then fear: *'Having had no such problem in the family before
how were we going to manage?'*
'What would our future life be like?'
'Worst of all would he survive?'

These reactions were intermingled with guilt, should I have phoned an ambulance, not taken him in the car, would this have improved the situation?

When he came home after his operation it was more of a mental strain than anything else. I did not leave him for more than a few minutes at a time in case something happened. At night, I lay awake listening to him breathing and worrying about the next day. I found it very difficult to let him take any control of his own life, I wanted to do everything for him.

Ironically the first time we attended a Support Group Meeting, a doctor gave a talk entitled 'Collusion' This really helped me, I made a point of accepting what had happened and letting my husband do what he felt he was able.

Unfortunately because of his job, it was decided by his G.P. that he should stay off work for several months. Although this did not cause financial problems, he became very depressed. Most of the depression was caused by loneliness as I worked full-time. This is something with hindsight that possibly could have been avoided if I had noticed sooner what was happening, perhaps the carer needs to be given more information regarding what effects the heart attack/angina/surgery may have on the patient.

To sum up, it does appear that heart disease in any form may change a persons personality and temperament, even if the change is only temporarily. A carer can feel isolated and must be encouraged to talk to other members of the family if possible, and/or to their GP. One of the most useful comments ever made to my husband and me, by a nurse at Cambridge: - 'Try not to think of yourself/your husband as a heart, but as a person.'



4. Happy Christmas 1995

My wife and I had just travelled about two hundred miles to spend Christmas with our daughter. About an hour later, my wife was in the cardiac ward of the local hospital, having suffered a heart attack.

Like the vast majority of people, I was under the impression that a heart attack was usually fatal. In the unlikely event of recovery, that the person concerned would be unable to take part in normal activities, spending the remainder of their days sitting about waiting to die. I was full of gloom and doom, my mother had died some three weeks earlier and now it seemed that my wife would be following her.

My amazement upon being told that my wife would only be in hospital for about seven days, and would be well on the road to full recovery in around six months. Nothing was too much trouble for the nursing staff, and they invited questions regarding the patient.

During the following weeks, my wife made extensive enquiries regarding rehabilitation and after much trouble made contact with the rehabilitation unit at our local hospital. (I would stress that this was in no way the fault of the hospital, but a lack of awareness by the local doctors at that time)

It was while she was attending the rehabilitation programme that she was made aware of the support group who visit the patients at the centre. It is entirely due to the efforts of the support group in providing exercise classes, that she was put well on to the road to recovery. Over the weeks, months and years that have followed, we have gradually returned to leading a full life, albeit not quite so energetic as before.

CONCLUSION

Hopefully the information, however brief in this booklet, will help you proceed along the rocky road of being a carer. You have an important and responsible role to play in encouraging the changes in the lifestyle of the person who has suffered an attack, and perhaps your own. Unfortunately heart disease is a product of the world we live in. We cannot change society overnight, but we can change and develop our own life and encourage others.

At times it will be a lonely road with another hill to climb, another river to cross. Supporting a loved one, relative, or friend will help and aid their recovery, but you may have to take on new responsibilities at home such as cleaning, paying the bill, gardening, and driving again. You may become anxious about their health, tending to be watching for any signs or symptoms more than they are themselves, and totally ignoring your own.

It is a situation that one has to adapt to, but you do not have to be alone. Help and advice is available from many sources, 'SO DO ASK' (See the section on **SUPPORT AND INFORMATION**)

Many carers have climbed the mountain with their patient and have safely come down the other side. In doing so, they have found their walking boots and swimming costumes again...GOOD LUCK!





Use this panel to make any notes



Produced by
the Coronary Heart Disease/Stroke Sub Group
of the Suffolk Health Improvement Programme (Suffolk HImP)

Printed January 2001