

YOUNG CARERS

Mental Health Resource Pack Making Young Carers Count in Tower Hamlets



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NHS
Tower Hamlets



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Helping you to understand and cope with mental health problems



Introduction

This resource pack is designed for young people up to 18 years who are helping to look after a relative or friend who has a mental health problem.

When a parent or other relative suffers from a mental illness it can affect your life too. People with mental illnesses and their families can feel isolated and ashamed at a time when they need help the most.

What people sometimes forget is that these people are unwell – people like your mum, dad, granny or sister who you desperately want to get better.

This booklet will help you to understand more about what is happening and who can help. Mental health problems are common and there are many people who can give you and your family help, advice and support. This booklet gives information about mental illness, what your rights are as a young carer and lists who you can contact for further advice and support.

With understanding and support from the family, school and mental health professionals, your relative's mental health is more likely to improve.



Living With Mental Health Problems

If your parent or relative suffers from a mental health problem, you are likely to be faced with behaviours and situations that you have never had to cope with before in your life. You may also have to cope with other people's attitudes to mental illness. Either of these can leave you feeling confused and isolated.



No one really knows what is going on in someone else's head. You may for example be in a classroom pretending to listen to a teacher but really you are thinking about what's on the telly tonight or about a party coming up. The teacher doesn't know this, because your thoughts aren't affecting your behaviour. You are sitting quietly in class apparently paying attention.

When someone has a mental health problem, they may be experiencing some very unpleasant thoughts and sensations which make them behave in a strange way. All of a sudden, the person you thought you knew seems to have changed and is behaving in a bizarre way. Their behaviour may cause pain, embarrassment or could be dangerous but they look exactly the same.

Living With Mental Health Problems

What Is Going On?

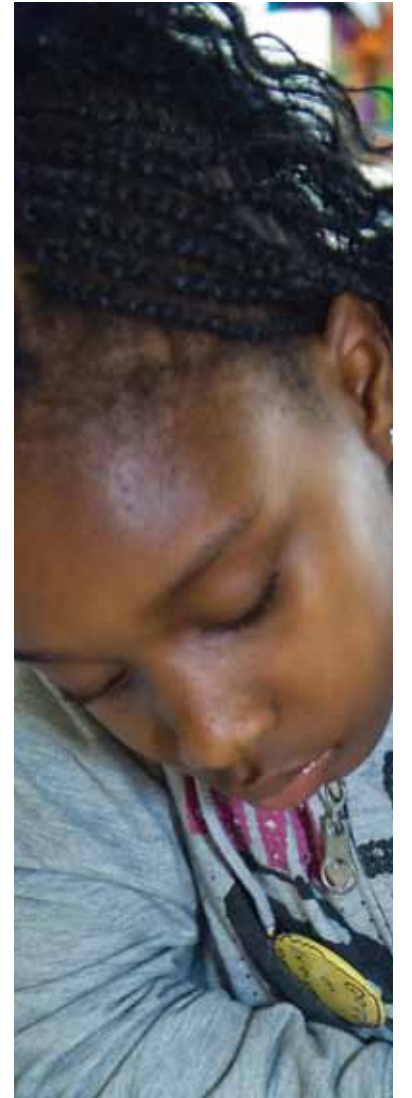
When a person has a cold, they sneeze. When a person has a mental health problem, they may shout or laugh at something that isn't funny or talk to themselves. Just as people can't help sneezing, other people can't help behaving in this unusual way. Their own world has been disturbed and they are trying to cope with this.

Sometimes your relative may say something hurtful to you. This happens because of their illness and NOT because of the way they feel about you. It is their illness talking and not them. They feel scared and confused and that could be how you are feeling as well.

It Can Be Hard To Talk To Others

People often feel embarrassed about telling others what is happening especially when there is an issue of mental health. It seems easier to say 'mum has a broken leg' than 'mum has depression'. Everyone can see a broken leg so they can see and understand what is involved but mental health is not so visible or easy to understand.

The words 'mental illness' often get very strong reactions from people, to the extent that they can miss or not focus on what is actually happening. The word 'mental' conjures up images of mad behaviour and perhaps memories of playground insults like 'nutter' or 'loony'. But the word 'illness' often gets forgotten. When people are ill they need treatment to get better, they need looking after and they may need to go to hospital.



Living With Mental Health Problems



Why Don't People Understand?

If someone is behaving strangely, other people can feel uncomfortable. They don't know what to do because they often do not know that the person is ill. Mental illness is often hidden so other people can't see what is wrong. There are none of the obvious signs like bandages, so they are unsure what the problem is or even that a problem exists. Sometimes people can be frightened, because they don't understand mental illness. What is important to remember is that the person who is ill may be feeling frightened too.

Living With Mental Health Problems

What Does It Feel Like?

Sometimes when you wake up in the morning after a dream, you feel a bit strange because the dream was so real. One minute you are dreaming and the next you are awake in bed but part of the dream lingers on. For a few moments it can be hard to tell what is real and what is the dream. Some mental illnesses have been described as being like bad dreams where you cannot wake up.

This could be a starting point to try and understand what your relative is going through. Imagine not being able to wake from the nightmare, or not knowing which part of a dream was real and which part was not.

Your attitude to your relative is so important. Sometimes it is difficult to be patient but if you think to yourself 'imagine what they are going through' this can help you to understand. Remember: they are not doing things to hurt or upset or anger you on purpose; they are doing these things because they are ill, frightened, have lost confidence in themselves, are feeling vulnerable or simply need support.



Remember: a person who is ill may be feeling frightened too

What About Me?

Things may have changed at home, either suddenly or over time. You may not be getting enough sleep or enough food. You may feel that no one is taking any notice of you. You may feel that what you are going through is a horrible nightmare and you wish that things could return to the way they were. You may feel very angry that other people don't experience the same problems. You may feel enormous pressure on your shoulders.

All of these feelings are normal and understandable.

What is Mental Health?

The word mental means 'of or involving the mind'. When someone talks about mental health they are talking about how well a person's mind is.

Most of us have times when we feel unhappy, moody or we may feel that we want to spend some time on our own. At other times we feel happy and full of energy. Both are to do with our mental health – how we feel or think about ourselves and the world around us.



What is Mental Illness?

If someone has a mental illness, it means that their mind is ill. Mental health problems can be diagnosed when a person's problems persist over a longer period of time and start to affect the way that the person thinks, feels and behaves.

These mental health problems can range from anxieties (worries) and phobias (fears) to a more severe mental illness where people are unable to cope with their day to day lives. When someone is struggling to cope in this way it may be best for them to go into hospital to get better. In other cases a GP may prescribe some medication to treat the illness or to help the person to relax or sleep. With the right treatment most people with a mental illness get better or are able to cope with their illness.

One of the main problems when dealing with mental health is trying to understand what is happening in someone else's mind. We all have thoughts and feelings that go up and down during the day. Mental health problems seem to occur when one or a number of thoughts override and block out any others. For example, some people may feel a sense of complete hopelessness about everything they do or they may think that someone is spying on them or able to read their mind. These ideas are very real for the person involved although they may seem odd or unusual to someone else. This is important to remember. It is part of the illness.

Mental illness is common. One in four people will become ill with a mental health problem at some point in their lives.



Remember: most people with a mental illness get better

Why Do People Become Ill?

The simple answer is that no-one really knows why people become ill. Every person is different and will react to situations in different ways according to their personality. It could be due to one factor or several.

These include:



Why Do People Become Ill?

Biological

Sometimes the chemicals in the brain aren't working properly and cause the brain to send out wrong messages. These messages can make someone have odd thoughts or feelings or behave in a strange way. For example, someone may hear voices talking to them and may talk back to them. The voices are very real to the person hearing them even though no-one else can hear them. The voices are produced by the person's own mind which has been disturbed by the chemicals in the brain not working properly. These chemicals affect our thoughts, behaviours and feelings. Medication aims to restore a healthy chemical balance.

Genetic

There may be a history of mental illness in a family which passes from one generation to the next which means that people in this particular family are more likely to suffer from depression in the future than other people. You may think 'I wonder if I will get it?' but having a family history of an illness does not automatically mean that you will get the illness too as many different factors combined lead to mental ill health.



Environmental

Sometimes things can happen in life which people find hard to cope with like the death of someone close to them, the break up of a relationship or the loss of a job. These events can be very stressful and can make a person more vulnerable to illness which includes mental health problems. Remember: you cannot cause someone else's mental illness.

Other factors which contribute to a person's mental health are whether they have a support network including their family or their friends, what other stresses are involved in their life and any experiences they have had earlier in life.

Remember: you cannot cause someone else's mental illness

Mental Health Problems



When illnesses are described, a health professional may talk about symptoms. Symptoms are indications of an illness, like for example red spots on the body are a symptom of measles. There are many different kinds of mental illness. We've tried to explain the main symptoms of some mental health problems in this section, so that you can understand more about them...

It is important to remember that the symptoms described here are not necessarily exclusive to a specific mental health problem. In many cases the symptoms are shared and are common to several disorders.

Mental Health Problems

Depression

People with depression feel very down and unhappy for a long period of time. They may not want to do the things that they used to enjoy. They may also feel tired but find it difficult to sleep while others may sleep for hours every day. Everything becomes much more difficult needing more effort than before. This can make people feel very vulnerable and over sensitive. These feelings can't be simply shrugged off which can be hard for people to understand. Sometimes depression can be so bad that people may feel like they want to kill themselves (feel suicidal). These thoughts need to be taken seriously so if you know someone who is feeling like this you should tell a trusted adult.

Schizophrenia/Psychosis

Schizophrenia and psychosis are conditions caused by an imbalance of chemicals in the brain. People with schizophrenia may have to take medication to get the chemical balance right. They may struggle to think clearly and may not be able to tell the difference between what is right and what is wrong. For example, they may have strange thoughts or beliefs, they may feel that they are being watched or badly treated by everyone. This can lead to feelings of anxiety, panic, anger, paranoia, confusion and fear. Many people cope well on treatment to control their problems.

Some of the symptoms of schizophrenia or psychosis include:

- false beliefs (delusions) e.g. believing that people are spying on them in the street or from the TV
- hearing voices e.g. these could be the voices of someone they know or someone from the past. The voices can tell them to do all sorts of things and can be good or bad
- muddled speech or thoughts e.g. they may get the days muddled up or you may not understand what they are saying
- loss of feelings or emotions e.g. they may not react as you expect them to or may not seem to care
- loss of energy which may make them behave out of character

Remember: most people cope well on treatment to control their problems

Mental Health Problems

Personality Disorders

It is not clear what causes personality disorders but previous traumatic experiences including mental, physical and emotional distress or abuse seem to be related to this.

Personality disorders can cause people to become:

- paranoid (overly suspicious without a reason)
- less able to make friends or socialise
- more nervous
- more emotional
- more dependent on other people
- angry very quickly
- liable to self harm
- emotionally switched off
- to have a sense of emptiness
- to have mood swings

Eating Disorders

- Anorexia Nervosa:
People with anorexia are often very underweight but believe themselves to be fat. They experience severe weight loss which is caused by starving themselves or over exercising.

- Bulimia:
People with bulimia crave lots of food though they may not be hungry, eat huge amounts in one go and then make themselves sick or take tablets called laxatives to get the food out of their bodies. They may seem to be in control of their lives but actually swing between eating far too much and then starving themselves.

Bi-Polar Disorder/Manic Depression

When people have bi-polar disorder, they have periods of time when they feel extremely happy (elation) followed by times when they feel extremely depressed. These feelings are difficult to control. When people feel really good they will have loads of energy and may find it difficult to sleep. They may take risks or do things without thinking about them first so for example, a person who is usually responsible with money may start overspending and quickly run up lots of debt. When they feel down, they may feel a lack of energy. They may feel hopeless or be withdrawn and want to be left on their own.

Mental Health Problems

Anxiety

Most of us feel a little nervous or anxious when we have to do an exam, meet new people or speak in front of a group. Sometimes when our hearts are racing and we feel nervous, this makes us try harder which helps us to cope with the situation next time it happens. Anxiety can become a problem when people become so worried that they can't cope with these situations, and can stop them from carrying out every day activities like shopping, travelling on a bus, or answering the phone. This level of anxiety can make people feel very unwell.

Obsessive Compulsive Disorder (OCD)

OCD causes people to repeat the same act such as washing their hands, over and over again. Some people for example can become completely obsessed with cleaning and keeping things tidy. Others will have worrying thoughts that they can't get out of their heads or will carry out actions repeatedly that don't need to be done like switching lights on and off a set number of times. If the person does not repeat these actions they will get in a lot of stress. This can get in the way of work or family life.

Phobia

Phobia is when a person is totally overcome by a fear or anxiety about something. For example if you are agoraphobic you are scared of open spaces and not able to leave the house.

Dementia

A person's ability to remember, think and reason is affected by dementia. People can forget names or events and struggle to complete every day tasks like getting dressed. People can become easily confused and get angry and frustrated as a result of what is happening to them. Dementia usually occurs in people in their mid 60s and older but people younger than this can be affected too. Dementia generally gets worse with age but the development of symptoms can be slowed with drugs or other treatments.



Treatment:

Diagnosis

The doctor will need to identify which illness your relative has. The doctor will need to see your relative and may want to talk to family members as well. Mental health problems can be hard to identify. It may be obvious to you that your family member is ill but not so obvious to a doctor who perhaps they haven't met before and who is only seeing them for a short appointment. Unlike you, the doctor won't see your relative everyday and so won't have anything to compare their behaviour to.

Diagnosis is important because it then guides the doctor to which treatment is most appropriate. This can include medication.

Dual Diagnosis

If your relative is addicted to alcohol or drugs as well as having a mental illness, they will be described as having a dual diagnosis. It is more complicated to support people with a dual diagnosis as it is difficult to treat their addiction and mental illness separately. Alcohol or drug addiction has a negative effect on a person's mental health, making their symptoms worse. It can also mean that any treatment they are getting for their mental illness (e.g. medication) won't work properly. People with dual diagnosis have more of a chance of getting better if they receive support from the dual diagnosis service.

Medication (Drugs)

Drugs work on the brain chemistry and tackle the symptoms of the illness. For example, if a person is constantly on the move and not getting any sleep, a tranquiliser will slow them down and will help them to rest. Or if a person is feeling very down and depressed, anti-depressants can help to lift their mood. Drugs can be taken in tablet form or by regular injections.

Although drugs can help a person to get better, they can sometimes have unpleasant side effects. These can include shakiness, stiffness, weight gain, a dry mouth or blurred vision. If you are worried about any side effects that your relative may be experiencing, talk to the doctor.

A person may have to try a number of drugs before they find the one that suits them best. Some people may have to take drugs for the rest of their lives; others may have to take

how can my relative get better?

them for a short period only. Sometimes people can get tired of taking the drugs and stop. For a while you may not notice a change in them but then after some time the effect of the drug will wear off and the illness will return. This is why it is very important to involve a doctor in any change to the treatment.

Most people on medication find that they can get on with their lives without too much interference from their illness.



Talking Treatment – Counselling or Psychotherapy

Talking about problems can help people find solutions and new ways of coping. This can happen on a one-to-one basis or in groups.

It could be very helpful for you and your relative to talk about what's happening at home. You can also talk to a counsellor on your own about what's going on in your mind and at home. In many cases this helps to make things clearer. It can be helpful to talk to people who have been through a similar situation themselves and to know that you are not alone – talk to the Young Carers project about this.

For relatives with mental health problems, there are also opportunities to come together and talk to people going through a similar experience

or who also suffer from a mental health problem. The organisations listed at the back of this booklet may run such groups, or be able to put you in touch with other people who can help.

With treatment, some people recover completely. Others may have problems that repeat throughout their lives. When someone becomes ill again this is called a relapse. You may be able to spot the signs when someone is close to relapsing and get in touch with people who can help.



Legal Matters - Who Can Help?

This section explains some of the laws which deal with mental health and with carers. These laws can be complicated to understand and in many cases you may not need to have dealings with them. The laws are important and help to guide and support you and anyone else involved with your relative's mental health.

Sometimes people become too unwell to stay at home and need to go into hospital but sometimes they might not realise that they are ill or they may just not want to go. When this happens, the law says that people can be taken into hospital, even if they don't want to, using the Mental Health Act. This is called 'sectioning' and can mean different things depending on which section of the Act is used.



Some of the most common sections of the Mental Health Act are:

Legal Matters - Who Can Help?

Section 2

This section lasts for up to 28 days to allow time for the person's mental state to be properly assessed.

Section 3

This section is for up to 6 months to allow the person to be treated in hospital until they are well again.

Sometimes, someone who has been placed on Section 3 can be put on a Community Treatment Order when leaving hospital. This means that even after going home, they will be seen regularly to check that they are keeping up with treatment. If they are not, they can be taken back into hospital without the need to be sectioned again.

Section 136

This allows the police to take the person to a 'place of safety'. This is only used if someone is thought to be in danger so that

the patient can be assessed by a doctor and approved mental health practitioner. The assessment must be made within 72 hours.

If a person who has been sectioned disagrees with the reasons for this happening, they have the right to appeal against the decision at the hospital.

If the person in hospital is the person who normally looks after you, it's important to know who will be looking after you while they are away. A close friend or relative may be able to do this. Sometimes, social services may arrange for a foster carer to do this until your parents or carer is well enough to look after you. Your views about this are important so don't be afraid to say what you would like. It's important to keep in contact with the person while they are in hospital and it may even help them to recover more quickly. You can arrange to see them in the 'Family Visiting Room' at the hospital (see the back of this leaflet for details).

When people are ready to leave hospital, a 'discharge' plan is drawn up by the hospital staff and other people who know them, to help them cope when they get home. This may mean that they get support from the 'Home Treatment Team' who can visit them at home to help them stay well. If you are a young carer you should also be asked what help you think you need.

Support and advice are available to help you cope. Under the law you are entitled to support by the local authority and the NHS.

The Children Act

Social workers employed by social services are expected to:

- respond to a young carers individual needs
- help to attain the services they need
- help and advise on practical and personal problems
- explain that they have a right to ask for a carers assessment

Legal Matters - Who Can Help?

When someone has a mental illness there are lots of different people who might help them. The most likely of these are:

GP/Family Doctor

GPs know about their patients' health and if something is wrong, they will try to work out what it is and what would be the best way to help. They might decide that a patient needs medicine and give them a prescription for this. If they need extra help they might 'refer' them to a Community Mental Health Team for support.

Community Mental Health Team (CMHT)

The CMHT is made up of social workers, community mental health nurses, psychiatrists, psychologists and other workers who can help people with mental health problems. There are four CMHTs in Tower Hamlets each covering a different area – contact details for each team are given at the back of this booklet.

Care Co-ordinator

When there are a lot of workers helping to look after someone with a mental illness, one of them in particular takes responsibility for co-ordinating the work. This person is called the Care Co-ordinator (usually a social worker or a nurse) and they will be the main contact person for the patient. The Care Co-ordinator is responsible for drawing up a Care Plan with the patient and should also include carers and relatives in this.

Legal Matters - Who Can Help?

Social Worker

A social worker is someone who supports people with problems such as mental illness and their families. They keep in regular contact to make sure that the person is receiving the right treatment and staying well. They can also help with different problems that might come up for the patient and other family members.

Community Mental Health Nurse (CMHN)

Community mental health nurses also provide support and advice to people with mental health problems. If the patient receives regular injections to treat their mental illness, these are given by CMHNs.

Psychiatrist

Doctors with special training for treating mental illnesses are called Psychiatrists. They can work out what the illness is and decide on the best treatment. They will meet with the patient at different times to check if the treatment is working or needs to be changed. If the patient seems unwell they will also help to make a decision about whether they should go into hospital.

Psychologist

Psychologists have special knowledge of what causes mental health problems. They can talk to a patient to find out what makes them unwell and how their illness affects the way they think. They can help people understand how their thoughts and feelings are connected and support them to try to see things differently so they will feel better.

Approved Mental Health Professional (AMHP)

When someone becomes very unwell, a decision has to be made about whether they need to go into hospital. These decisions are made by psychiatrists and approved mental health professionals with special training in mental health.

Home Treatment Team

This team of Doctors, Nurses and Social Workers can provide extra support when someone is unwell, visiting them at home so that they don't need to go into hospital for treatment. They might also support someone coming out of hospital to help them and their family to manage while they settle back into home life.

Five Top Tips To Help You



1

Talk to someone you can trust about what is going on

It can be a huge relief and a release of stress to be able to get things off your chest. This could be from your teacher, another relative, a good friend, a doctor, social worker or from the young carer's project. It could be from a telephone helpline where you can remain anonymous (not give them your name) if you prefer. Some contact telephone numbers are at the back of this booklet.

2

Look after yourself

Make sure you take breaks and have fun. This is often easier said than done – you can spend so much time worrying about your relative that you may forget about yourself. But this means eating properly, sleeping and making sure you find the time to spend on things you enjoy like swimming, shopping or being with your friends. Try to stay in touch with your friends and don't become isolated.

Five Top Tips To Help You

3

Learn as much as you can about your relative's condition and the treatment they receive

Knowledge about their illness will help you to deal with the situation and know what to expect.

4

Remember that your relative's condition is not your fault – you cannot cause the illness



5

Try not to argue with your relative

Wait until things calm down and then you will find it easier to get your point across. More often than not you are arguing with the symptoms of the illness and not the person themselves. Arguing will only raise the tension.

If the person you care for says something strange or hurtful try to remember that this may be because they are ill. If their words or behaviour worry you, tell a trusted adult.

Glossary of Terms

What does that mean?

Young Carer

You might not see yourself as a Carer but if you live with someone who has a mental illness, the chances are that you spend some of your time looking after them and supporting them to stay well. As a Young Carer you have the right to receive support so that you have a better chance of doing well at school, as well as being able to join in activities you like with other children. Your local Young Carers' Project will be able to help you with this (please see the back of this booklet for details).

Assessment

Assessment is a way of checking how well someone is and what type of support they might need. For example, your relative with a mental illness will have had a mental health assessment at some point to find out if they were ill and how professionals should help them with their illness. You have the right to have a 'Carer's Assessment' to work out what support you need.

Confidential

If something is confidential it means that it is private information. When you tell a professional something personal to you then that information has to be treated carefully. The professional should not share it with anyone else without making sure this is ok with you first.



Glossary Of Terms

CPA (Care Programme Approach)

When someone needs to be seen regularly by a Psychiatrist and a Care Co-ordinator, the support they get is part of what is known as the CPA. As part of this, the Care Co-ordinator is responsible for writing a Care Plan with details of the treatment and support they need to help them stay well.

Referral

There are many different professionals or teams who can support you and your family. Before starting to help though, most of these people need to be given information in the form of a referral. This usually means someone filling out a form with details like your names, address, phone number and what support is being asked for.

Respite Care

If you are the main person looking after someone who is ill, this can be difficult sometimes if you need to be somewhere else or if you need a break. Respite care is when arrangements are made for someone else to look after the person you care for so that you can have some time away.



Key Contacts

SCHOOL:

In school you may want to talk to your teacher or school nurse for advice. Or you can call any of the following contacts:

CHAMP PROJECT:

The CHAMP Project supports families where a parent has a mental health problem.

For general information about the CHAMP Project please contact:

Email:
CHAMP@towerhamlets.gov.uk
Telephone: 020 7364 0409
Or: 020 7364 2054

ADULT MENTAL HEALTH:

To speak to someone in your area contact the Children's Specialist in Adult Mental Health using the details below.

For families living in Isle of Dogs & South Poplar and Bow & North Poplar, contact:

Isle of Dogs: 020 7791 8299
Bow: 020 7364 5569
Mobile: 07506 714 235

For families living in Stepney & Wapping and Bethnal Green, contact:

Stepney & Wapping: 020 7791 3701
Bethnal Green: 020 7364 1050
Mobile: 07930 619 082

EDUCATION:

Education enquiries can be directed to the Specialist Teacher at:

Telephone: 020 7364 6440
Mobile: 07506 712 128

YOUNG CARERS PROJECTS:

The Carers Connect Service supports young carers and their families living with someone who has mental health problems. It is run by Family Action and is based at:

Albert Jacob House
62 Roman Road
London
E2 0PG

Carers Connect Project Telephone:
020 7364 3497

General Enquiries
Telephone: 020 7364 3491

Email:
carersconnect@family-action.org.uk
Website:
www.family-action.org.uk/youngcarers



Key Contacts

YOUNG CARERS GROUP:

Young carers aged between eight and 18 years are welcome to attend. The project aims to give young carers the opportunity to take a break from the daily responsibilities of being a carer. It is an opportunity for them to mix with other young carers in a social setting and engage in sports and leisure activities as well as providing them with advice and guidance in any issues concerning them. Activities include art, drama, photography, canoeing, biking, climbing and other activities as decided by the young people who attend.

Through club based and non club based activities the young carers will be supported by personal advisors to develop their self esteem and self confidence through group based activities.

Separate group sessions are held for each of the following age groups:

- Age 8 to 13
- Age 13 to 18

To find out when these group sessions run, please contact:

Telephone: 020 7364 5834
Or come and see us:
The Urban Adventure Base
150 Burdett Road
Mile End Park
London
E3 4JT

THE FAMILY VISITING ROOM AT MILE END HOSPITAL:

Mile End Hospital
Bancroft Road
London
E1 4DG

JOURNEYS CHILDREN'S BEREAVEMENT AND LOSS SERVICE:

Journeys Children's Bereavement and Loss Service provides counselling to children and young people aged 3 to 16 in Tower Hamlets who are bereaved or experiencing other significant loss.

This is based at:
3 Merchant Street
E3 4UJ

Telephone: 020 8981 9691

Alternatively you can Email:
therapy@journeys.org.uk

or visit the website:
www.journeys-cbls.org.uk

DUAL DIAGNOSIS SERVICE:

Specialist Adult Mental Health Service for service users who experience mental health and drug/alcohol problems. Tower Hamlets adult residents can be referred by health care staff and non-statutory organization staff, please call for more details.

Burdett House
Mile End Hospital,
Bancroft Road
London E1 4DG,

Telephone: 020 8121 5503

Fax: 020 8121 5495

