

4. Whole family recovery

“It’s not about waiting for the storm to stop, it’s about learning to dance in the rain.”

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The impact of mental health problems on the family

Mental health problems are likely to have a significant impact on the whole family. In addition to disturbing symptoms such as hallucinations and delusions, families must cope with troubling behaviours that often accompany the onset of a mental disorder. For example, self-neglect, possible suicide attempts, trouble with the law and lack of awareness about having a problem. How everyone in the family copes with the impact of mental health problems will have a significant effect on your relative, partner or friend's recovery and ability to live a fulfilling life.

Some families find that dealing with the mental health problems can lead to an enriched relationship with their relative. Others have reported self-growth that they have found strengthening and valuable. There is also a strong possibility of increasingly close relationships between family members as they undertake the journey of recovery together.

The experience of families is shaped by a variety of factors. How you, and your family, are affected by your relative's mental health problems may be influenced by:

- your emotional reactions to having a relative with a mental health problem
- your pre-existing relationship with your relative who has mental health problems
- the nature and severity of the disorder
- other stress-producing conditions that may exist in your family
- the kinds of coping mechanisms and communication patterns within your family
- the particular circumstances and resources of your family
- your family's wider support network.

The heavy demands of care may lead to burnout... The cost of time off work and extra support can create a severe financial burden for families. Both the care requirements and the stigma attached to mental illness often lead to isolation of family members from the community and their social support network..

There is no question that any serious mental disorder affects the whole family and changes the way everyone goes about their daily life. The challenges that mental health problems bring affect the entire family – parents, spouses, siblings and children – both young and adult. Relationships within the family may undergo changes. There may be a disruption of normal social and leisure activities.

When families first learn that a relative has a mental health problem, they may experience a number of emotions including shock, fear, sadness, guilt, anxiety, confusion, compassion, understanding and even anger. These are all perfectly normal and natural reactions and it is important to realise this is part of a normal process of coming to terms with what has happened.

Some people are relieved to finally learn a reason for the changes they see in their relative. Others hope the diagnosis is wrong or that there has been some mistake. Families may experience anger and resentment if they feel powerless in changing their relative's situation.

Feelings and attitudes are also likely to change over time. Guilt is an emotion experienced by many families. A common reaction is that the family feels they are somehow responsible for

the mental health problems. It is very important though to understand that no one can cause mental health problems.

Grief and feelings of loss are also common among family members of a person with mental health problems. You may grieve over the loss of the person you feel you knew or feel lost opportunities for anticipated successes (eg college or career plans).

Families may find they need to grieve and work through a re-evaluation of their expectations and hopes. When mental health problems result in conflict, disruptions to family life and financial burden, family members may find themselves experiencing alternating feelings of anger and guilt.

Families sometimes feel they ride an emotional rollercoaster – when their relative is doing well they're hopeful and optimistic but when their relative relapses, they are often devastated.

Understanding and acknowledging your feelings, as uncomfortable as they may be, is important. Try to explore where they are coming from and think about strategies for how you can develop ways of dealing with them.

Maintaining hope amidst ambiguous loss

Mental health problems, especially when severe or long-lasting, are often associated with a number of perceived losses for everyone affected by the mental health problems. These may include:

- loss of the person as they were before the mental health problems began
- loss of personal goals and aspirations
- loss of ordinary family life
- disruption to relationships.

Mental health problems can result in a sense of 'ambiguous' losses for the family. These losses can be ambiguous in the sense that, while the loved family member is still physically present, psychologically they may have changed and the person we knew may appear to no longer be there.

The losses incurred through mental health problems are sometimes termed 'ambiguous' since our society does not recognise them. Unlike other losses, such as a death in the family, there is no formal ceremony or ritual during which mourners receive support from others, followed by closure of some kind. With mental health problems family members suffer the ambiguous losses, unmarked by a date or by outside recognition, which can make the losses seem very isolating and unshared. It is therefore important to acknowledge your feelings of grief and loss and to share them with someone you can trust - a family member, friend, counselor or support group, for example.

In her book, *Ambiguous Loss: Learning to Live with Unresolved Grief*, Pauline Boss describes how mental health problems present a form of ambiguous loss in the sense that the relative with mental health problems is still present in body, but maybe not in mind at certain times. She explains that the goal for the recovering family is to balance grief over what was lost with participation in what is still possible.

Stages of grief

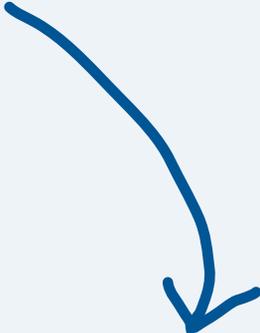
Grief is a natural reaction to loss. Grieving takes time and everyone will have their own way of grieving. Elizabeth Kubler Ross suggested that people move through different stages as they come to terms with a loss.

Grief is not necessarily experienced in the order of stages presented. People often move back and forth through these stages, skip a stage or go through two or three simultaneously.

The family recovery journey involves learning the daily dance of balancing losses that mental health problems can bring, with persistent hope for improvement. Hope can become a source of strength in learning to manage what can feel like an almost overwhelming sense of loss.

Two partners in the dance of recovery: loss and hope

In recovery, families embark on a journey of accepting limitations and losses within a new world of possibility. Recovery is a balancing act between expectations and what is possible, between finding a path to a better future and



Shock Feeling empty and numb.

Denial *"This is not happening. My family relative is just going through a difficult time, this is only temporary."*

Anger at the unfairness of having to deal with mental health problems.

Bargaining *"If only we could have a miracle. I'll try to spend all my free time with him to get him back to the way he was."* At this stage it can be common to feel blame toward mental health services: *"If only they done their job at the beginning then this would not have happened."*

Depression As acknowledgement of the mental health problems sets in, it can bring feelings of sadness: *"We've lost so much."*

Acceptance Coming to terms with the fact that your relative has mental health problems and learning to live with it and move on.

accepting the inevitable difficulties that lie ahead on that path.

In a paper entitled, *Recovery and the Conspiracy of Hope* (1996), Patricia Deegan explains that recovery is not an end point in itself but rather an ever-deepening acceptance of limitations from which spring unique possibilities. She says:

This is the paradox of recovery - that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.

This is the 'dance' of recovery.

The challenge of recovery is to maintain a balance between over-expectation and under-expectation... to encourage progress without fostering failure.

Loss

Dealing with mental health problems will often involve dealing with changes in your relative, partner or friend including changes in personality, behaviour, and in ideas of 'what they could have become' – and with subsequent changes in family relationships. This may only be for a certain time while they regain their health or there may be elements of change that will be lasting.

Depending on the role of your relative within your family, their mental health problems can alter how family members relate to one another. For example, mental health problems can exacerbate existing relationship problems but can also draw family members closer together.

Losing the way your relative was and life the way you knew it poses challenges for all the family. When severe mental health problems walk into your family, life is different and the future often looks less bright and uncertain.

This mother's comment shows how her hope for recovery in the future is held in opposition to the grief for what has been lost to the illness:

I just want him to be what he was like.... Just being able to work and having a full life, that's what I hope for, for my son. I even have a picture in the sitting room, a picture I look at when I sit in there. It's a picture of him when he was younger, when he was laughing and so I'm going to leave it there because that is what I'm going to see in the future. Bland & Darlington, 2002

Maintaining hope and a positive attitude

It is not uncommon for families to be torn apart by mental health problems and it is necessary to nurture the realistic hope that members will be able to come back together again as a whole family, and to work toward that as a goal.

It is important to recognise this process may take time and you may face numerous challenges on your journey. Research confirms the enormous importance of hope in the path of recovery and shows that hopefulness appears to be central to a family's ability to cope with the impact of mental health problems.

At times you may feel without hope. This is a natural reaction. During these periods it can

be helpful to get support from mental health professionals or a carer support worker. They are experienced in working with families who are at this stage in their journey.

Coping with loss and grief

Each member of the family will have their own individual way of coping with the emotions and reactions they experience. Below are some suggestions for you to try that may help:

Don't be afraid to reach out for support

Friends, extended family, support groups, and/or a professional counsellor can help

Be patient with yourself – it takes time to adjust to significant changes

Acknowledge and share your feelings with others who understand what you are going through

Be good to yourself. Make time for activities you enjoy

Know your limitations so you don't find yourself overburdened by responsibilities

Writing in a journal or diary is helpful for some people

Maintain a healthy and balanced lifestyle for you and the rest of the family.

Carers' recovery

COOL (Carers' One to One Link) started discussing recovery for carers in 2000, when a carer realised she needed and wanted to recover her own life, even though the person she cared for, and about, was not able or willing to recover his own life at the time. She realised she too, was stuck in his mental health problems which was the main focus of family life. All revolved around being mentally unwell. She wrote this piece for other carers based on her personal experience.

The chaos that ensues is emotional, physical, practical and social. It threatens the ability to love and cherish. It prompts a desire to get away. It engenders denial and a need to be absolved of guilt. Sometimes it gives rise to the real fear of the personal safety of anyone involved. Jobs are threatened and friendships seriously disrupted. This is a personal disaster which often with little warning, rips apart the fabric of life, challenging values and distressingly altering expectations for the future.

Recognition that grief plays a large part here

What is needed is consolation, comfort, kindness and hope. Achieving tranquillity, by whatever means, is a major objective along the recovery highway. You have done all you can or more than you should. Nothing seems to make a difference. You are the main carer and closest. You bear the brunt of the person's 'illness' and share the isolation, helplessness and fear.

You have tried everything, you are exhausted, depressed, feel guilty – “*what have I done wrong?*” You feel bereaved – you have lost someone you were close to. You do not know this new person. And then everything seems OK, for a while, until the next time. This leaves you on tenterhooks, alert for any sign of change.

Often this is happening well before someone becomes a client of mental health services and before you realise your additional new role as carer, as well as being partner, parent, child, sibling etc.

- Relatives and friends may have been caring on their own for years, months, weeks
- people generally know very little about mental health problems
- families often don't know that help is available or where to find it
- people want to cope, and find ways of coping until a crisis develops, beyond their scope
- often the carer knows the person cared for intimately
- carers can get stuck at the point where their relative becomes ill, caught up in the strangeness of it all
- it's different for everyone.

When services become involved

- Services must listen and respond to carers
- carers must be involved and included in planning and treatment. They often know

the client best – having lived, loved, worked and had fun with them, maybe all their life.

- carers must be helped to consider their own needs regarding what they want and are able to do, and changes they want or need to make for their own wellbeing and for the person they care for.
- be real and honest.

Detaching with love

Setting boundaries Not tolerating abuse from anyone. Mental health problems are not an excuse.

Consider your own needs for sleep, family, friends, socialising, work, leisure activities, spirituality and ensuring these needs are met.

Risk Allowing the person to face the consequences of their actions ie no longer rescuing. If we keep rescuing, we may inadvertently create a dependency and be helping people to keep on with their self-destructive behaviour and not find the help they need to embark on their own journey of self discovery. This idea comes from AA, where people have to hit a rock bottom before they themselves decide to get well.

Developing faith The person is on their own personal journey.

Developing trust They can handle life and its challenges – with support. They are not helpless.

Letting go of total responsibility for ‘caring’ by developing good relationships with professional staff and trusting them to do their bit. Engaging other family members or friends and trusting them also.

Setting a vision or goal for recovery of relationships - what could this look like?

We have a good relationship, see each other regularly, enjoy each others company and lead our own lives.

Vision for carers' personal recovery

Carers leading a full life Able to maintain equilibrium in face of the ups and downs of the person you care for and about.

Ability to detach with love *"I am not abandoning you. I am trusting you to find your own recovery path when you are ready. I am here to help you when I can."*

Acceptance of what is Life isn't going the way you thought it might and all your feelings; anger, guilt, depression, sadness, bargaining and acceptance are part of the grieving process and have been acknowledged and integrated.

Ideas about how to get there

1. Taking responsibility
2. Develop a healthy self-regard
3. Keep the focus on your own recovery
4. Professionals develop a healthy regard for carers, and carers for professionals
5. Get the support you need. For example, see friends, join a support group, see a nutritionist or other complementary therapist, counsellor, carer support worker, or find other ways to get the emotional support you need ie talking things through with friends, reading self-help books, attend courses on recognised grieving, co-dependency etc
6. Be willing to invest in yourself, spend time, money and most of all care for yourself. Do whatever it takes
7. Be gentle with yourself, allow yourself to make mistakes. Be forgiving. You have been through a lot
8. Know that it will take time. The grieving process can take two years and personal growth is a life-long process
9. Introduce things you love to do at times when you would have made a sacrifice to meet the needs of the person you care for
10. Consult yourself daily as to how much you actually want to give
11. Let go of obligations and responsibilities that are not yours and over which you have no power or control
12. Have fun and enjoy yourself sometimes.

JOY CAN RETURN.

Enhancing resilience within the family

Research has shown that while some people seem to be naturally resilient, this behaviour can also be learnt. You cannot control the course of your relative's journey, but you can make changes to lessen the impact on your own wellbeing. You can also look at ways of supporting your relative in developing their own techniques of increasing their psychological resilience.

By developing your own resilience you will be modeling positive change for your relative and for the whole family. The following are just a few of the techniques you could work on in order to increase your own resilience.

Nurture positive beliefs in your abilities Self-esteem plays an important role in coping with stress and recovering from difficult events. Remind yourself of your strengths and accomplishments. Becoming more confident about your ability to respond and deal with a crisis is a great way to build resilience for the future.

Develop a strong social network Having caring, supportive people around you acts as a protective factor during times of crisis. It is important to have people you can confide in. While simply talking about a situation with a friend or loved one will not make troubles go away, it allows you to share your feelings, gain support, receive positive feedback and come up with possible solutions to your problems.

Accept that change is a part of living Certain goals may no longer be attainable because of adverse situations. Accepting circumstances that cannot be changed can help you focus on the ones you can alter. Flexibility is an

essential part of resilience. By learning how to be more adaptable, you'll be better equipped to respond when faced with a crisis. Resilient people often utilise these events as an opportunity to branch out in new directions. While some people may be crushed by abrupt changes, highly resilient individuals are able to adapt and thrive.

Maintain a hopeful outlook An optimistic outlook enables you to expect that good things will happen in your life. Try visualising what you want, rather than worrying about what you fear. Staying positive during dark periods can be difficult, but maintaining a hopeful outlook is an important part of resiliency. Being an optimist does not mean ignoring the problem in order to focus on positive outcomes. It means understanding that setbacks are temporary and that you have the skills and abilities to combat the challenges you face. What you are dealing with may be difficult, but it is important to remain hopeful and positive about a brighter future.

Nurture yourself When you're stressed, it can be all too easy to neglect your own needs. Losing your appetite, ignoring exercising and not getting enough sleep are all common reactions to a crisis situation. Focus on building your self-nurturing skills, even when you are troubled. Make time for activities you enjoy. By taking care of your own needs, you can boost your overall health and resilience and be fully ready to face life's challenges.

Look for opportunities for self-discovery People often learn something about themselves and may find they have grown in some way as a result of their struggle with loss or change. Many people who have experienced tragedies and hardship have reported better relationships, greater sense of strength even while feeling vulnerable, increased sense of

self-worth, a more developed spirituality and heightened appreciation for life.

Avoid seeing crises as insurmountable

problems You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Try looking beyond the present to how future circumstances may be a little better. Note any subtle ways in which you might already feel somewhat better as you deal with difficult situations. Keep things in perspective. Even when facing very painful events, try to consider the stressful situation in a broader context and keep a long-term perspective. Avoid blowing the event out of proportion.

Take decisive actions to solve problems Act on adverse situations as much as you can. Take decisive actions, rather than detaching completely from problems and stresses and wishing they would just go away. Simply waiting for a problem to go away on its own only prolongs the crisis. Instead, start working on resolving the issue immediately. While there may not be any fast or simple solution, you can take steps toward making your situation better and less stressful. Focus on the progress that you have made so far and planning your next steps, rather than becoming discouraged by the amount of work that still needs to be accomplished.

Develop your problem-solving skills Research suggests that people who are able to come up with potential solutions to a problem are better able to cope with problems than those who cannot. Whenever you encounter a new challenge, make a quick list of some of the possible ways you could solve the problem. Experiment with different strategies and focus on developing a logical way to work through common problems. By practicing your problem-solving skills on a regular basis, you

will be better prepared to cope when a serious challenge emerges.

Establish goals and move towards them Crisis situations are daunting. They may even seem insurmountable. Resilient people are able to view these situations in a realistic way, and then set reasonable goals to deal with the problem. When you find yourself becoming overwhelmed by a situation, take a step back to simply assess what is before you. Brainstorm possible solutions, and then break them down into manageable steps. Instead of focusing on tasks that seem unachievable, ask yourself *"What's one thing I know I can accomplish today that helps me move in the direction I want to go?"*

Keep working on your skills Resilience may take time to build, so do not become discouraged if you still struggle to cope with problematic events. According to Dr Russ Newman, "research has shown that resilience is not an extraordinary thing but is rather ordinary and can be learned by most anyone" (2002). Psychological resilience does not involve any specific set of behaviours or actions, and can vary dramatically from one person to the next.

Focus on practicing some of the common characteristics of resilient people, but also remember to build upon your existing strengths. For example, some people write about their deepest thoughts and feelings related to trauma or other stressful events in their life. Meditation and spiritual practices help some people build connections and restore hope.

The key is to identify ways that are likely to work well for you as part of your own personal strategy for fostering resilience.

Setting boundaries and limits

As a family, you will need to decide how much support you can provide and the conditions under which you can provide that support.

While you can't force someone to seek treatment or change their behaviours, you can set standards and boundaries for what you can and will live with when a relative has a mental health problem.

When we are placed in a caring or supporting role, we often want to do as much as possible to help the person. In doing this, we run the risk of overextending ourselves and responding to the needs of others at the expense of our own needs. We may feel obliged to help out of guilt, sincere desire, fear of hurting the person or our own need for approval by others. Understanding your own needs is not selfish – it is healthy and it is also setting a positive role model for your relative.

In order to best help your family, find some time to sit down and evaluate what you and other family members can realistically do. Communicate the limits of the support you can provide and the expectations you have of your relative.

Keep in mind that establishing boundaries is a process. Take your time and look for small ways to begin. It may be helpful to get some support in thinking about the impact your caring role is having on you and to look at ways you can start to make more time for your own needs. Carers support workers can help you do this and they are experienced in working with families in similar situations. It may be helpful to meet other families who have had similar problems in the past.

It's OK to expect basic rules of conduct and

cooperation. We all require these to get along with each other. Be aware that feelings of guilt may prevent families from effectively setting limits and realistic expectations for their relative.

If, as a family, you decide that your relative will be living with you, it may be necessary to set reasonable limits on what behaviours will be tolerated. Some of these rules may be for the benefit of your relative – others may be for the benefit of the whole family.

You should anticipate that the limits may be tested and make it absolutely clear to your relative that rules will be enforced if necessary. For example, you may decide that in the event of physical violence or property damage, you will call the police. Your relative should be aware that violence is not acceptable and that you will call the police if they become violent.

Some of the rules and expectations you and your family may want to discuss and decide upon may include:

How much financial support you are able/willing to provide

Whether or not you are willing to co-sign papers, eg a lease, loan or credit card, for your relative

Your relative's ability to live in your home

How much practical help you can provide – meals, budgeting, food shopping etc

What household tasks you expect your relative to do

Personal hygiene requirements ...

Disruptive behaviours such as refusing to follow house rules, playing music too loudly, neglecting to show up for family meals, being argumentative, etc

Use of tobacco, alcohol and/or street drugs in your home

Gambling

Attending medical appointments

Taking prescribed medications

Issues that may affect family safety.

If you are feeling strong and healthy you will find it easier to set and maintain healthy boundaries. Sometimes this can be difficult if you are exhausted and you have been struggling to look after yourself. One way to start creating boundaries is to start saying 'no' to other people so you have time to focus on your own needs and welfare.

How to say 'No'

Lots of people find it very difficult to say 'no.' Some might feel they are being rude or unkind. They might worry that the other person will be upset or won't like them anymore. They might feel guilty about saying 'no,' thinking that the other person's needs are more important than their own.

You have the right to say 'no' and have your needs met – and so does everybody else. In so doing you are refusing a request and not rejecting a person. It can be particularly hard to say 'no' to people you are emotionally involved with.

However if you say 'yes' to everything then you will probably become overloaded and exhausted. In time you might well start to blame others for this. Remember that it is better in the long run to be truthful about your needs and limits than breed resentment and bitterness within yourself.

Here are some tips you can try when you want to say 'no:'

Be straightforward and honest but not rude

Keep it brief

Tell the person if you are finding it difficult

Be polite – say something like *"thank you for asking..."*

Speak slowly with warmth, otherwise 'no' may sound abrupt

Don't apologise and give elaborate reasons for saying 'no'. It is your right to say no if you don't want to do things

When saying 'no' take responsibility for it. Don't blame others or make excuses.

Change *"I can't"* to *"I don't want to."*

Six different ways of saying 'no'

1. **The direct 'no'** When someone asks you to do something you don't want to do, it's OK to just say 'no'. The aim is to say no without apologising. The other person has the problem but you do not have to allow him or her to pass it on to you. This technique can be quite forceful and can be effective with salespeople
2. **The reflecting 'no'** This technique involves acknowledging the content and feeling of the request, then adding your assertive refusal at the end. For example *"I know you want to talk to me about organising your weekend but I am too busy today."* Or *"I know you would like to go to the cinema tonight but I can't come"*
3. **The reasoned 'no'** In this technique you give a very brief and genuine reason for why you are saying 'no.' For example *"I can't have a late lunch with you because I have to pick up my child from school"*
4. **The raincheck 'no'** This is not a definite 'no.' It is a way of saying 'no' to the request at the present moment but leaves room for saying 'yes' in the future. Only use it if you genuinely want to say yes in the future. For example *"I can't see you this week but I might be free sometime next weekend"*

5. **The enquiring 'no'** As with the raincheck 'no' this is not a definite 'no.' It is a way of opening up the request to see if there is another way it could be met. For example *"I cannot go to the zoo with you this weekend but is there another time you'd like to go?"*

6. **The broken record 'no'** This can be used in a wide range of situations. You have a simple statement of refusal and just repeat it over and over again. It is particularly good for persistent requests. For example:

Jenny: No, I don't want to go on holiday with you.

Tom: Oh go on, it's a really good deal!

Jenny: I'm sure it is but I don't want to go on holiday with you.

Tom: Oh please, I'll pay for you.

Jenny: Thank you but no, I don't want to go on holiday with you.

Tom: Is it because you're too busy? You can bring your laptop with you!

Jenny: That's a nice idea but no, I don't want to go on holiday with you.

Coping with stigma

While there are issues related to external and practical matters such as dealing with financial matters and looking for suitable housing or work, it is also very important to plan in advance what to say to friends, relatives, neighbours, and co-workers about your relative's mental health problems and the potential problems and challenges it raises in your life.

In different arenas of your life you may encounter some of the ignorance and prejudice that has historically surrounded mental health problems and the stigma associated with it. But it is important to recognise that you may also find you are pleasantly surprised and other people start to talk about their experiences of mental health problems within their own family – 1 in 4 people will experience mental health problems. It will be up to you how you decide to talk to other people about what you are experiencing.

Talking to 'outsiders'

Prejudices about mental health problems are based on a lack of accurate information or first-hand experience. Consequently, the best way to respond to outsiders you encounter is by speaking out about it knowledgeably.

It is unfortunate that in addition to everything else you have to contend with, you also have to educate people about mental health problems. On the one hand, you already have so much stress in your life that you have little energy left over for this task. On the other hand, your direct experience puts you in the best position of being able to speak with authority and compassion. Those who care about you are likely to pay attention to what

you say because they are concerned about you.

You may find it useful to prepare several ways of describing your situation. You can then choose the way that best suits your mood and the situation.

When you are with close friends or relatives, you might give more detailed explanations of what has happened to your relative and the impact it has had on you and the rest of your family. You may want to share the diagnosis, prognosis, and any information you have learned about mental disorders, as well as the confusion, heartache, and sadness that you have experienced.

With people you do not know very well, or with neighbours, you may want to give a very short version. They may need to know only that your relative is suffering from a biological illness that sometimes affects the way they behave. You can assure them that they are not dangerous and tell them that they ought to just say hello if they see them outside, even if they appear to be talking to themselves.

When you run into former friends of yours, or of your relative, remember you can give as much or as little information as you like. You can say your relative has been having a hard time but you do not feel like talking about the situation. Or you can go into detail, discussing the diagnosis and a summary of their history. The only rule is to do whatever works best for you and which is not harmful or hurtful to your relative.

People will usually follow your lead regarding how much to discuss the situation. Do not expect your friends to ask how your relative is doing if you never bring up the subject yourself. It is wise to assume that most people

who care about you want to be sensitive to you and to your family, but it is also wise to assume that most people do not have a clue how to do so. People with a relative who has mental health problems often feel hurt by friends who feel awkward about the situation and with the best of intentions, say or do the wrong thing.

Educating your friends, colleagues, and relatives puts yet another burden on you, but this is one we strongly encourage you to embrace, at least for a few important people in your life. Otherwise you are likely to find yourself in the all too common position of feeling further isolated and resentful of friends and relatives. Deciding you cannot talk to anyone about one of the most significant parts of your life is bound to take its toll. Most of your friends and relatives need to hear no more than a few of the basic facts. If they want to learn more, you can offer to get them some information on the topic.

Telling people how they can be supportive is also important. Try to spell out whether you want your friends and relatives to ask you about the situation. If it is not helpful to you for people to offer advice, it is important to tell them so. You can let them know whether their efforts to cheer you up feel good.

It is also important to keep in mind the limitations on how much you can change relatives, friends, and the general public. Often family members who become active in fighting for the rights of people with mental health problems want everyone in their family to do the same. It is essential that each family member respects the ways in which other family members cope with the situation.

It is important not to forget that no matter how much a relative tries to distance themselves

from their relative with a mental health problems, they cannot escape the impact entirely. Everyone has to go through their own journey of coming to terms with mental health problems. The path and pace will differ significantly from one person to another.

Talking to children about mental health problems

Mental health problems can be frightening – not only to the person who has the mental health problems but also to people around them. For a child relying on the care of an adult who has mental health problems, things can be even more confusing. Children may have a number of questions, such as “*Why is my mum or dad this way?*” “*Will I become this way?*” and “*Who will take care of me if my mum or dad is sick?*”

If a child you care for has a parent with mental health problems, it is important to take time to address their questions and concerns. Helping a child understand their parent’s or guardian’s mental health problems will make things seem less ‘frightening’ and give the child the tools they need for a more confident, safe and happy life. Here are some tips that may help when talking to a child about mental health problems and answers to some commonly asked questions.

Ideas to encourage conversation

It can be less threatening to start by asking children why they think their mum/dad sometimes acts ‘differently’ or ‘strangely,’ then use their comments or questions as an opening to talk more about mental health problems.

If you think a child wants to talk to you but is afraid to open up, there are some questions you might want to ask them. It is important to remember, though, that if a child does not want to talk to you, you should not force them. Just let them know that you are there for them and ready to listen if they do want to talk.

Children may feel guilty about being embarrassed by their parent’s mental health

problems. Ask a child about the way their parent acts and how it makes them feel. Explain that mental health problems can make parents act in strange, confusing or scary ways sometimes, and ask how that makes them feel.

Children often feel responsible for their parent’s mental health problems or feel as though these are somehow their fault. Asking a child if they ever feel as though there is something they could do to make the problem go away or if they somehow feel they are to blame for the way their mum/dad has been acting is one way to start this conversation. However, it is very important to be very careful that, in asking, you don’t imply (or let the child feel you imply) that this is somehow their fault.

Another approach might be to say, “*You know I sometimes wish there was something I could do/or wish I had done differently to make your mum/dad better. But I know that mental health problems are nobody’s fault . . .*”

If a child asks you a question you don’t know how to answer, be honest and tell them you don’t know, but you will try to find out.

Helping children with their feelings

A child’s feelings may vary depending on how old they are and how much they understand about their parent’s mental health problems. For example, younger children often feel guilty or afraid while older children may tend to feel more anger and embarrassment. You can try some of the following tips to help them:

- create an atmosphere that would encourage children to talk about their feelings

- talk about your own feelings so that they have a positive role model
- take advantage of moments that lend themselves to a discussion of feelings, for example when watching a television show about a parent who becomes disabled or unwell
- be available to listen, but don't pressure a child to talk about feelings if they aren't willing.

These are some things you can attempt to do when children try to express feelings:

- give them your full attention
- make eye contact
- check out what you are hearing in their words or interpreting from their behaviour.

For example, *“So you're really angry at your father and me because of how much of my attention he takes?”* or *“You've been slamming doors all night. Are you angry about something? I'm here if you want to talk.”*

If the feelings shared by a child arouse strong feelings in you, eg anger, sadness or guilt, resist the temptation to jump in. Becoming judgmental or emotional while the child is talking can prevent them from talking more, both now and in the future. It takes great self-discipline to not become judgmental if a child is having feelings you think they shouldn't have. You might be tempted to say *“You shouldn't be angry with me. You should be thankful. I'm the one keeping the family together.”* Try not to give in to these temptations; a child needs to express their emotions (even difficult ones) in order to better understand and learn from them.

Try to provide the child with skills for handling strong feelings:

- explain that feelings are neither right nor wrong. It's OK and natural for them to have the feelings they're having
- emphasise that talking about feelings can be helpful and that you'll always try to make special time when they need to talk
- explain that feelings do not have to control what we do.

Give examples such as *“It's OK that you're angry with dad and I, but the way you're acting toward us now is not OK”* or *“Being embarrassed about your mother's mental health problems doesn't have to stop you from explaining it to your friends.”*

Humour can help to make the whole communication seem positive if it isn't used to discount or ignore your children's feelings.

Helping children understand the disorder

Try to start with yourself. What are your attitudes and knowledge about mental health problems? The more you know, the better you'll be able to answer their questions matter of factly.

The stronger your attitude that mental health problems are somebody's fault, the greater risk you run of saying and doing things that can make the child blame their parent or others. It is important to:

- find out how the child explains their parent's behaviour
- build on what the child says: acknowledge any truth in what they say

- respectfully correct anything that is based on wrong information or fantasy. For example, *“Daddy isn’t acting this way because of anything you or I have done”*
- use language and explanations that are appropriate to each child’s age and intelligence, using examples that are familiar to them.

For example, you might say to a 5-year old:

“Do you remember when you had the chicken pox? You cried a lot, you didn’t feel like doing anything and you were grouchy toward all of us. It wasn’t because you didn’t love us or wanted to be that way but because you didn’t feel well. Right now your mummy doesn’t feel well. That’s why she’s crying a lot, not doing anything and acting grouchy. She still loves you and me, but she can’t show it right now.”

Whereas you might tell a 10-year old: *“You know how parts of our bodies get sick sometimes, like when we get stomach aches or sore throats. Well some people get sick in the part of their brain that controls feelings. That’s what’s wrong with dad. He has an illness in that part of his brain that controls feelings. This illness has a name. It’s called bipolar disorder.”*

If a child has witnessed violent or suicidal behaviour, situations requiring police intervention or any other traumatic incidents, it is important not to underestimate how terrifying this experience can be. You can explain to the child that their parent didn’t know what was best for them at the time and explain how the doctors/police/whomever are going to help their parent.

Children learn from what they see others doing, so try to behave, speak, and have the same kind of attitude you would like to see in them.

Helping children feel good about themselves

Children, like adults, get angry when something unfair happens to them. At some point, children will probably ask themselves *“Why did this have to happen to me/our family?”* You can help by making sure they understand that life is unfair sometimes and gives no ‘guarantees,’ but that they did nothing to deserve this problem.

Children of parents with mental health problems often worry they will inherit problems themselves, especially if the parent’s mental health problems involve feelings, thoughts, or behaviour. They need lots of reassurance that they are ‘normal’ or OK. If they do have a problem, they need to know that many other people have problems too, all problems can be discussed and most problems can be solved, or at least managed.

Make sure a child understands that they aren’t ‘bad’ or ‘sick’ if they have unpleasant feelings like anger, jealousy, sadness, fear, or embarrassment. These feelings come and go in everyone. It helps to talk about them with someone they trust.

Having more information often helps people cope better and reduces negative feelings. There are many advantages to explaining the mental health problems to children and answering their questions:

- children often imagine things that are worse than reality; the truth is often not as bad as they fear
- being honest with children helps them trust you
- understanding that there’s an illness involved can help children feel for and respect their parent

- understanding can also help reduce their anger and guilt about what has happened
- being informed also lessens the risk of any anger and mistrust a child might feel if left to discover on their own that their family life differs from their friends' during episodes of crisis.

Being informed also lessens some of the vulnerability, sensitivity, confusion and surprise a child might feel when confronted with negative comments from others about their parent.

Helping children feel safe and secure

During stressful times in a family, children need reassurance that someone will take care of them. Opposite are some ways to help children feel more confident and assured of their safety and stability.

Just like you would prepare a child for what to do in case of a fire or being approached by a stranger, tell them exactly who to call and where to go if something happens that scares them when they are alone with their parent and they can't reach you. For example:

“Go to every neighbour we know until you find someone who is home. Ask them if you can use their phone. Call the phone numbers I've given you until you reach someone. That person will tell you what to do next. Stay with the neighbour until you reach someone on the list and you know what to do”.

Children who have lived in very stressful situations are often tense and watchful in order to detect early signs of trouble or danger. Make sure the child knows it is OK to relax, have fun and feel good, even if their parent is

A consistent routine helps children feel safe. The more predictable and structured the environment, the better most children will feel

Explain to children that sometimes talking can help and keeping things in may make them feel worse

Help children identify which adults and which friends they trust and like to talk to when they are feeling upset. Encourage them to talk to these people. If they choose you, try to be a good, non-judgmental listener

Make sure children know what to do and who to call if they don't feel safe, especially if they are children of a single parent, or if their parent has a history of violence or suicide attempts

Encourage them to tell you or someone they trust whenever something happens that upsets or scares them.

unwell or things are stressful at home. Explain to the child that even though their parent may have done or said things that hurt them, their parent loves them very much, does not mean to hurt them and is very sorry.

Ask children what they do to feel better when they are feeling upset, scared, hopeless, or unsafe. If they are coping in ways you think are destructive, help them figure out better ways. School guidance counsellors or mental health professionals can help access support for helping them develop healthy coping strategies.

Here are some practical suggestions for helping a child to respond to their parent:

Share any of the discoveries or skills you have learned about what works and doesn't work in dealing with their parent. For example, *"I know it's upsetting when mummy talks about the food being poisoned, but arguing with her about it doesn't help"*

Make sure the child understands that even though their parent is experiencing mental health problems, it's OK for them to protect themselves from any behaviour that seems scary or dangerous.

Give specific suggestions for how to protect themselves. You may want to make a rule that the child tells you whenever a situation involving their parent has scared them or made them uncomfortable and teach the child to tell their parent whenever they are scared or upset by them.

Let a child know that showing their parent they still love him/her is very important. Consistently make it very clear that it is not acceptable for children to be disrespectful to their parent or you.

Here are some practical suggestions for helping children respond to other people about their parent:

Asking or expecting children to keep the mental health problems a secret can be extremely difficult for them

What you say and do with others regarding the mental health problems will probably influence the child more than anything you tell them to do so try to be a good role model for matter-of-fact communication about the illness

Explain to the child that many people don't understand mental health problems and it may scare them; they may try to make fun of it; they may have ideas that aren't true; or they may change the subject or say nothing

Teach a child how to explain the mental health problems to others. The more children understand, the easier it will be for them to explain to others.

It helps to practice with them how they might respond to questions or comments. Children of any age can be cruel to each other, so it is important to prepare a child to deal with teasing from other children. Here are some tips for helping children know they don't have to bear the burden of keeping their parent's mental health problems a secret:

- explain to children that even though other families may have mental health problems too, many people still don't understand

that mental health problems are a real disorder, not just somebody acting ‘crazy’ on purpose

- help a child realise that when they try to talk about their parent’s mental health problems, other children (and even adults) may make fun of it, may have ideas that aren’t true, or may not know what to say.

Try to practice with them what they might say to help people understand the mental health problems and stop teasing. For example:

My dad does that because he isn’t well. I wouldn’t make fun of your dad if he was sick. Please don’t make fun of mine.

If you really understood what is wrong with my mother, I don’t think you’d say that. She has a mental health problem that makes her do that. She’s taking medicine and trying to get better. It’s really hard for me, so don’t tease me about it.

It’s important to encourage children to ask questions. Let them know you think questions are good, even if there aren’t always answers. By encouraging discussion, you will be helping to keep the lines of communication open.

Responses to some commonly asked questions

Why is my mum/dad acting this way?

Your mum/dad has mental health problems. Mental health problems are illnesses that affect the brain, which is where we control our feelings, thoughts and behaviour. Sometimes mental health problems can make people say things or do things that they would not normally do if they were feeling healthy. There are many different kinds of mental illness. Here are some of the big names doctors have for some of them: depression, bipolar disorder, schizoaffective disorder, schizophrenia, obsessive compulsive disorder, and panic disorder. (If there is a diagnosis, you might want to tell the child the diagnosis in order to reinforce the idea that their parent has an illness that doctors can name.)

Is this my fault?

Mental health problems are nobody’s fault. You didn’t cause your mum’s/dad’s mental health problems and you are not responsible for making them go away.

Can I ‘catch it’ or become unwell like them?

Mental health problems are not like a cold. You can’t ‘catch’ it. Just because your mum/dad has problems does not mean you or I will have them. Scientists still don’t know what causes mental health problems, but they are trying to find out.

Will things stay like this?

Most people who have a mental health problem are helped by taking medicine, going into the hospital, or talking to people who are trained to help them. (Talk with the child about ways their parent is trying to get help, or

reasons why they may not be seeking help. For example, “Your dad doesn’t want to take medicine because it’s too scary for him to admit he has mental health problems” or “Your mum doesn’t want to go to a doctor because she is scared the doctor will make her go into the hospital again.”)

Do mum and dad still love me?

Yes. Your mum/dad is acting strange/scary/remote because they aren’t very well, not because they don’t love you anymore.

Why is this happening to me/us?

Doctors don’t know why people get mental health problems, but you are not alone. Many families have someone with mental health problems (1 in every 4) and many of them manage to cope as a family. There are a lot of other children who have someone in their family with mental health problems, but they may be too embarrassed or scared to talk about it, so you don’t know. (Ask the child if they know any other children who have someone with mental health problems in their family.)

Young carers’ projects

If you are concerned that mental health problems in the family are having an impact on a child you are caring for you can find out about the local Young Carers’ Project. Young Carers’ Projects are run by trained support workers who deliver services specifically for children and young people who have someone in their family with mental or physical health problems.

The project will support a variety of respite/ break activities, enabling the young person to get a break away from their responsibilities at home, the opportunity to mix with young people of their own age and have some fun. See page 144 for more details.