

Working with
children
of parents with a serious illness



Supporting teachers, leadership teams and professionals in primary and junior secondary schools

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Children of parents with a serious illness

A large number of children live with a parent who has a chronic, distressing or possibly life-threatening illness. The parent may have a mental illness, such as depression or schizophrenia, a terminal illness such as advanced cancer, a chronic illness such as diabetes or heart disease or an episodic or acute short-term condition such as severe migraine. These parents may require hospitalisation or suffer from short- or long-term periods of being unwell at home.

Often, children of seriously ill parents may be reluctant to tell school staff and others of the parent's illness. This may be for a number of reasons, including the fear of being treated differently, not wanting to make others feel uncomfortable, or the fear of the associated stigma (particularly for children of parents with a mental illness).

Effects of living with a seriously ill parent

Growing up with a parent with an illness can be stressful. Some children take on a caretaking role or assist with jobs around the house when the parent is unwell. The level of stress and anxiety experienced by the child is likely to depend on a range of factors including:

- the attitude of the ill parent towards the illness
- the child's understanding of the illness, medications and various treatments
- exposure to negative effects of the illness, such as psychotic episodes, vomiting, anaphylactic reactions and physical changes such as hair loss
- the support the child receives from the parent and other significant adults
- the level of support the child is expected to offer when the parent is sick, such as chores and caretaking
- the personality and coping skills of the child.

Many children living with a parent with an illness cope remarkably well and may become more organised, empathetic and independent than other children. It is important to offer support to these children if needed, as well as to children who are not coping so well.

Children who do not cope so well can be overwhelmed by feelings of anxiety, guilt, anger and isolation. Research shows that these children tend to hide their feelings and frequently do not have a proper understanding of the parent's illness¹. They tend to be worried about issues related to their parent's illness, such as thinking they have caused the illness, that the parent may be sick or hospitalised forever, or that they might develop the illness themselves.

¹ Marsh, D.T. & Dickens, R.M. (1997). *Troubled journey: Coming to terms with the mental illness of a sibling or parent*. New York: Cambridge Press



Indicators that children may be experiencing difficulties

Indicators that children may be experiencing difficulties coping with their parent's illness may include:

- incomplete homework
- poor concentration in class
- a decrease in academic performance
- messy schoolwork
- unkempt appearance
- tiredness
- irritability
- being withdrawn, tearful or aggressive
- an increase in absences from school
- an increase in somatic complaints, including stomachaches and headaches
- disengagement from peers or changes in friendships
- over-willingness to please
- over-helpfulness
- perfectionism.

These changes in behaviour tend to coincide with a change in the parent's health, such as during and following a period of hospitalisation. However, many children who are suffering from anxiety in relation to their parent's illness may not present with obvious or dramatic symptoms. For some children, school is a safe place and they are able to 'tune out' from the demands of the parent's illness and focus on participating in school and enjoying time with their friends.

The above symptoms may also be related to other major life changes or problems experienced by the child or the family. It should not be assumed that unusual behaviours are necessarily a result of the parent's illness. You or other school support staff such as the principal or school psychologist should investigate the possible reasons for any behaviour change.

When to seek additional assistance

Children of a parent with an illness may need additional support and assistance if you notice major changes in behaviour and attitude, or persistent difficulties in coping with everyday school demands.



Strategies to support the child with a seriously ill parent

Provide social and emotional support

Assist the child to build and develop social networks and connections at school.

- **Encourage the development of friendships.** It is important that the child has friends of similar age who they can talk to and have fun with. If the child is having difficulty making friends, link them with one or two classmates who have similar interests or who are willing to be friends.
- **Check in regularly with the child.** It is important for the child to know they have supportive adults in their life they can trust. Regularly set aside time to listen to the child privately.
 - **Ask how the child is going.**
 - **Listen to the child in a supportive, non-judgemental way.** It is important to listen and to answer all of the child's questions honestly and sincerely. If you do not know the answers to their questions, let the child know you are unsure, too.
 - **Offer assistance** if you can.
 - **Acknowledge and validate the difficulties the child is facing,** for example 'That must be very scary for you' or 'It is normal to feel sad if we can't see our mum when she is sick.'
 - **Ask the child what they can do in the short-term to help themselves feel okay.** If the child lacks ideas, provide a strategy, such as saying 'You might like to have Mum's photo in your school bag' or 'You can make a card for your Dad.'
 - **Take care with responses.** It is not helpful to say: 'I know how you feel'. This takes ownership of the child's feelings away and may make the child less likely to speak to you in future. It is also not helpful to say 'Everything will be fine.' If things do not turn out okay, the child will lose trust in you and will no longer come to you for support.
- **Know your limits.** If you are uncomfortable talking with the child about their home life and the parent's illness, speak to the principal to ensure that someone else such as the school psychologist, special-needs coordinator or another teacher with whom the child has a strong bond can be the child's support at school. Tell the child privately that there is a special person the child can go to when they need to talk about what has happened or is happening.
- **Encourage links to groups or teams.** Encourage the child to join school groups or teams or outside activities such as sport, drama, choir or other special interest groups. This will provide an outlet for the child to have fun and build social support networks.
- **With parent permission, help link the child with organisations for children with an ill parent.** There are organisations and programs designed for children of parents with mental and other illnesses. Ask your school psychologist or deputy or assistant principal for more information on appropriate agencies; check the local community directory for possible links or do a web search.

Establish contact with the family and maintain regular communication

- **Set up an initial meeting with the family** in consultation with the principal, the deputy or assistant principal or the leadership team in the school. It may be helpful to have the school psychologist. At the meeting, discuss with the family:



- what support they would like from the school
- what support the school can provide
- who will be the school contact person when the parent is ill, such as the other parent, another adult family member, paid carer or community advocate
- the preferred method of communication, such as monthly meetings, phone calls, emails.

It is important to respect the family's wishes in relation to the illness even if you do not agree with them. Maintain confidentiality and respect the child and the family's privacy except where you are concerned for the child or parent's safety. Remember, it is not against the law for a parent to have a serious mental illness.

- **Provide practical assistance to the child and the family**, particularly when the parent's illness is worsening or they have been hospitalised. During these times, keep in contact with the designated contact person. Ask what the school can do to help and gain consent to provide assistance. Depending on the circumstances, it may be necessary to do one or more of the following:
 - **Assist the family with arranging alternative transport to school.** At times it may be difficult for the parents to physically transport the child to school. In such cases, organising the school bus to pick up the child, or helping to organise a car pool with other parents known to the family can be helpful.
 - **Provide the child with an alternative location to do homework.** Some children may find it physically and or mentally difficult to do homework once they are home. Provide a place at school such as homework club or the library where the child can complete homework.
 - **Understand and accommodate for financial difficulties.** At times, parents may be unable to afford excursions, uniforms, school camps or other school-related expenses due to their illness. If possible, make allowances for this and inform the school principal of the issue.
 - **Provide the child with lunch.** At times the parent may be unable to make or afford the child's lunch. Arrangements may be able to be made to provide food from the school canteen or lunch providers for the child for short periods.
 - **Allow extra time for class work or reduce the amount of work expected.** It may be hard for the child to concentrate and stay on task, particularly if the parent's health has recently deteriorated or if they have been hospitalised. It may help to modify the child's workload. For example, reduce the number of questions given, or ask the child to write half a page on a topic rather than a whole page.
 - **Allow the child to take small breaks or 'down time' if required.**
 - **Make exceptions when the child is late for school or has not completed work.** The child may be late because it is difficult for the ill parent to get ready, or they may have been visiting the parent in hospital. If lateness or incomplete homework becomes a consistent pattern, talk to the child and/or the non-ill parent or designated adult family member. It may be necessary to consult with the parents and request the principal to authorise a later start for the child for a period of time.
 - **Understand that parents may not be able to participate fully in school events.** Help ensure the child has one adult family member or significant adult attend in place of the parent.



Teach pro-active problem solving and coping strategies

Some children with an ill parent tend to engage in unhealthy coping behaviours such as, avoidance, worrying or acting aggressively.

- **Create a classroom activity around coping.** For example,
 - Ask your students, 'What do you do when you feel scared, worried or angry? What makes you feel better?' This can be done during circle time or as part of a discussion after reading a relevant book or watching a short film or animation.
 - Encourage children to use healthy coping strategies such as seeking help, writing a diary or exercising rather than unhealthy behaviours such as hitting, avoiding tasks or people or not talking. An activity could be structured around writing or drawing 'Five things that help me to feel okay' and 'Five people I can go to when I need help'. During this activity, help the child to list at least three adults, including one school staff member.
- **Increase the amount of fun, physical activities in your classroom.** Exercise or physical activity can help to reduce time spent worrying. It can distract the child from worries and release endorphins that make them feel good. Engaging in exercise can also make it easier for the child to get to sleep, rather than lying in bed worrying at night.
- **Teach your whole class relaxation exercises.** It may be beneficial to use relaxation exercises such as deep breathing, progressive muscle relaxation, or guided visualisation with the whole class. Tell the class they can use these techniques when they feel worried to help them relax. Immediately after lunch break is a good time to practice relaxation techniques in the classroom, as it will help children to refocus on the afternoon's activities. See relaxation activities on the Psych4schools website.

Provide the child with accurate age-appropriate information

- **If they have not already done so, encourage the child's parents to:**
 - **provide the child with age appropriate explanations** of the illness, expected duration, medication and treatment, and possible side effects. Honest answers will reduce the child's anxiety and help prevent the child developing incorrect ideas
 - **reassure the child that the illness is not their fault.** Younger children may believe they are somehow responsible for the parent becoming sick. It is important the child knows the illness was not their fault.
- **Never assume the child is 'using' the family situation to get out of work.** Children of parents with an illness usually don't put things 'on' as they do not want the illness impacting on anything. They don't want to hear 'Oh, poor you.' These children want to be like other children.
- **Teach the child/ and or the class simple lifesaving techniques and practice them once a month.** This will help to replace the child's anxiety around the parent's illness with a sense of being able to help. For example, teaching a child whose father has anaphylaxis:
 1. If Dad can't breathe run and get the Epipen and call 000.
 2. Tell the telephone operator three things:
 - a. Your Daddy can't breathe
 - b. Daddy has anaphylaxis
 - c. You have an Epipen.



If the child talks to you about a traumatic event that occurred as a result of their parent's illness

- **Provide a safe place for the child to talk about the trauma** if they wish to do so. If you do not feel comfortable talking with the child about what has happened, make sure you organise someone else to do so. This may be a school psychologist or another staff member at the school with whom the child feels connected. Actively discourage the child from telling other children about the event—emphasise that this story is best told to an understanding adult.
- **When talking with the child** about the experience, the following is important.
 - **Listen to the child if they wish to tell the story.** Children who have experienced traumatic events often want to tell and retell their story. However, if the child does not want to talk about the experience, do not insist that they do so.
 - **Refrain from asking for details of what happened.** Let the child guide the discussion. Avoid asking questions as you may inadvertently heighten the child's anxiety. In the early stages following the trauma, it is important that the child is not encouraged to talk about anything beyond what they wish to reveal.
 - **Acknowledge the child's feelings.** Use statements such as 'It must have been very scary' or 'That must have been so hard for you.' Remember, there is no right or wrong way to feel.
 - **Normalise the child's feelings.** Let the child know that other children would feel scared, sad or angry in that situation. 'It is normal to feel sad when you have had a dad in and out hospital so many times.'
 - **Increase the child's feelings of safety.** When doing so, acknowledge what has happened in general terms; emphasise that it is in the past and the child is now safe; and normalise the child's feelings and help the child look ahead. For example: 'You saw your Dad have a heart attack. That was really scary, but now he has had the operation to fix his heart and the doctors and nurses are looking after him. He is okay now, and your Mum says he is going to get better.' It is important to validate the child's emotion as a normal reaction to stress.
 - **Talk with the child about 'safe people'.** Safe people to whom they can turn to discuss the event at school may include the school principal, school psychologist, classroom teacher, or other staff at the school. If this connection is not established with the child, the child may share the details with other students who do not have the emotional resources to cope with the disclosure or to support the traumatised child. In addition, listening may traumatise other students.
 - **Provide support** to anyone who listens to the child's trauma story.
- **Protect the child from questions about the event.** Teachers can use techniques such as 'protective interrupting', where the teacher actually interrupts if they believe that a student is about to enquire about the event or the child is about to disclose to other students some traumatising information.
- **For further information see the Psych4Schools ebooklet 'Working with children who have experienced a traumatic event in the past two weeks'** for further tips and strategies as it becomes available on the website.



If the child talks to you about a recent event that may be considered abuse or neglect

- **Speak to your principal and report any abuse or your belief of abuse to the appropriate government department without delay** if you are concerned that the child's wellbeing is at serious risk. If the child informs you or you suspect neglect or abuse, ensure you follow your mandated legal obligations to report to the relevant authorities². Most schools have guidelines about who to consult when child abuse is suspected. This is often the principal or another senior staff member. Follow your school guidelines or protocol.
- **Record all actions taken** including what was said or observed to warrant the report, relevant meetings with senior staff members and the child's family, and discussions with the child protection authority in your state or territory. Sign and date the notes and keep them in a confidential place, such as a locked filing cabinet.
- **It is also considered best practice to inform the child (if age appropriate) and family** that you or the school will be making the report and why. This is not advised, however, if you believe that informing the family will place you or the child at risk of harm. See the document '*Reporting child abuse for teachers. What to do if you think a child is being abused*' on the Psych4Schools website, for further tips on feeling more comfortable making a report and how to talk with parents about making the report.

Resources

Websites for children of mentally ill parents

- Children of Mentally Ill Consumers
www.howstat.com/comic/Home.asp
- Children of Parents with a Mental Illness
www.copmi.net.au

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² See <http://www.aifs.gov.au> and search for 'mandatory reporting of child abuse' for guidelines by state and territory.