

A workbook for children
aged four to 10

When someone close has **MND**



This book belongs to _____



MND Connect

MND Connect is our advice and information service for children and grown-ups. Telephone calls and emails to MND Connect are confidential. This means when you talk to us we won't tell anyone else, unless you want us to.

You can telephone 08457 62 62 62 (low cost call)
or email youngconnect@mndassociation.org

MND Connect is available Monday to Friday from 9am until 5pm,
then 7pm until 10.30pm



When someone close to you is ill

Sometimes people close to us become ill.

Someone close to you has an illness called motor neurone disease. This is a long name for an illness, so we sometimes call it MND for short.

Not many people get MND, so it's not surprising that a lot of adults don't know much about it.

Some adults might not have even heard of MND before.



This is my picture of

They are living with MND.



What is MND?

There are hundreds of muscles in our bodies and we use a lot of these to move and do things.

Before our muscles move at all, they need to receive instructions from the brain. These instructions are sent to the muscles by nerves. The nerves that control the muscles are called motor neurones.

So if you wanted to throw a ball, a message would be carried from your brain, along the nerves to the muscles in your hands and arms to tell them to throw. This happens so quickly that you don't actually feel the message you just throw the ball without thinking about it.

When someone has MND something goes wrong with the nerves, which we call motor neurones. Gradually fewer and fewer messages get through.

When this happens the muscles won't move properly. If none of the messages get through, then the muscles will not be able to move at all, no matter how hard the person tries.



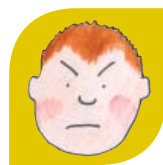
Motor Neurone Disease (MND for short)



Motor neurones carry instructions from the brain to the rest of the body.



If they stop working properly the instructions get muddled or don't get to where they're supposed to go.



Motor Neurone Disease (MND for short)



Then bits of the body don't know what they're meant to do.

- If the legs don't get their instructions walking can be a bit tricky
- If the lips don't get their instructions it's difficult to talk



Nobody knows why motor neurones stop working but doctors and scientists are trying to find out.



So what causes MND?

We don't know. But a lot of research is going on all over the world to try and find the causes and find new treatments.

Scientists and doctors are working hard to try and find out why this happens. One day, we hope that we will have a cure for all kinds of MND. This would mean doctors would be able to make people who have MND well again.

We do know that MND isn't catching, so you can't 'catch it' from someone else.

Do children get MND?

Children don't get MND. Only grown-ups get MND.

MND is most common in people over the age of 55.



What can MND do to the body?

The main effects of MND are on the muscles in the arms, legs, mouth and throat. But not everyone will have all of these problems.

Arms and hands

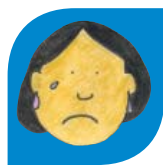
MND can affect the arms and hands. If someone has problems moving their arms and hands they may find it difficult to lift, hold and carry things.

Some people may find it difficult to put their clothes on and take them off.

Some people with MND cannot move their hands and arms at all.

There is equipment which can be used to help people who have difficulty using their arms and hands.

For example someone who cannot use their hands because of MND, might use a telephone that has a speaker and a microphone so that you can hear the other person and talk back to them without having to lift anything up.



What can MND do to the body?

Legs and feet

When someone has problems moving their legs they can find it difficult to walk, stand or climb stairs. They might find it hard to balance and may fall over.

Some people with MND use a walking stick, a walking frame or a wheelchair to help them get around.





What can MND do to the body?

Mouth and throat

We use a lot of muscles in our mouth and throat when we eat, drink, talk and swallow. For some people with MND, it is these muscles that stop working.

When this happens, their voices may sound different to how they used to. You might find it hard to understand what they are saying.

If the person with MND isn't able to speak they will still enjoy listening to you talk about what you've been doing. This can help them not to feel lonely or left out.

Some people with MND use equipment to help them communicate. They might use a board to spell out what they want to say, or a special computer that speaks for them.



What can MND do to the body?

Eating

Some people may find it difficult to eat and drink. They may also eat more slowly than they did before they got MND.



At meal times they may find it easier to eat food that is mashed up. This sort of food doesn't need chewing and is easier to swallow.

Some people with MND may find it difficult to eat enough to keep them going. If this happens they may decide to have a small operation to put a feeding tube into their tummy. The tube takes food straight to the person's tummy without them having to chew or swallow it. The person with MND might not need to use the feeding tube all of the time.





What can MND do to the body?

Breathing

Most people with MND will experience weakness to their breathing muscles at some time.

Some people decide to use a small portable breathing machine called NIV (Non-Invasive Ventilation) to help them breathe.

The person with MND uses a face or nose mask that is attached to the breathing machine. Air comes into the mask and is then pumped into the person's lungs.

The person with MND might only use the breathing machine for short times during the day or night.

Most people who use a breathing machine find it helps them to sleep better and that they have more energy during the day.





What changes have you noticed since the person close to you got MND?

You can write about these changes here or draw some pictures.



Being a young carer

A young carer is a child or young person under 18 years old, who helps look after someone close to them regularly.

You might be doing more to help around the house, or helping care for your brothers or sisters. Some young carers may even help the person living with MND to get washed or dressed.

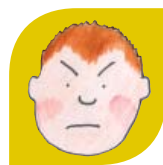
It can feel good to help, but sometimes you might feel worried, angry or upset. You may not have as much freedom as your friends.

If the person with MND lives with you, other people from outside of the family may also help with caring for the person with MND. It can be easy to get annoyed if they don't do things the way you do or you don't think they understand how the person with MND wants to be cared for.

You can't do all of the caring yourself. So if you spend a lot of time caring, remember that you need a break too.

Remember, it is okay to want things for yourself even while you are looking after other people close to you.

There is a lot of help and support on hand for you too. MND Connect can give you information about organisations that help young carers like you.



Feelings

Most people with MND do get tired more easily than they did before getting MND. So they may need to rest a lot.

Sometimes they may feel angry that they can't do some of the things they did before. This might include some of the things that most of us do every day like getting dressed, or going to the toilet. They may feel cross because they have to ask for help to do these things.

Some people living with MND find the illness makes them cry more easily than before and others find it makes them laugh. Sometimes the person with MND may laugh or cry at things they wouldn't have done before they got MND. Sometimes their laugh sounds different from how it did before they had MND.

Most people living with MND still 'feel' things the way that you do. They can still hear, think and see like they used to. They can still feel pain if they are knocked, or have to sit in one position for too long.

If talking is difficult, they will usually find other ways of letting you know what they want to say. It could be with a smile or a frown even. There are lots of other ways they might show you too.

Whatever happens, they are still the same person inside and will feel the same way about you.



How are you feeling?

If someone close to you has MND it can make you feel very sad. You might be sad that they are not able to do things that they used to. Sometimes you may feel like screaming or crying.

Don't feel silly or ashamed if you feel this way. It is really normal to feel like that.

Sometimes you might feel so sad that you want to cry. Crying can make you feel better – don't think that you have to keep all your feelings hidden inside.

If the grown-ups close to you seem quiet, sad or upset, they may be worrying about the person with MND, just like you are.

So don't think you have made them upset. It isn't your fault. And do try to remember they haven't stopped loving you, they just might be finding it hard to show you at the moment.

No-one can feel sad all of the time.





How are you feeling?

If you are feeling happy and are having fun, that is great. It's important for you and important for the person who is ill, to see that you are having fun and enjoying yourself.

You may feel angry at times, this is normal.

Perhaps you feel angry because the person you are close to has MND. You may feel angry because the person with MND is getting a lot of attention and things have changed now they have MND.

Grown-ups sometimes feel angry for the same reasons. Or perhaps you feel guilty about feeling angry or just feel mixed up inside but can't explain how you feel.





How do you feel?

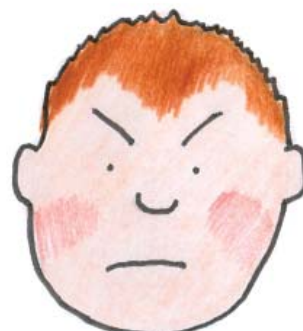
These are some of the different feelings we have when someone close to us is ill. There is a space at the bottom for you to draw yourself.



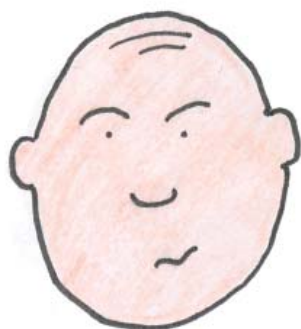
sad



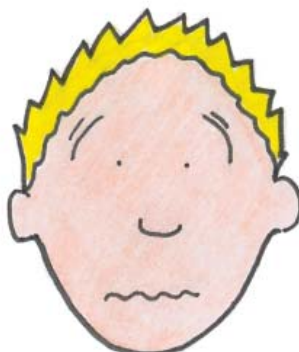
happy



angry



confused



frightened



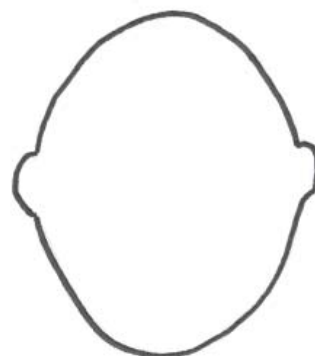
excited



lonely



disappointed





Feeling angry?

Here are some ideas of things you can do if you're feeling angry.
Add your own ideas in the blank boxes.



blow bubbles



scrunch up scrap paper



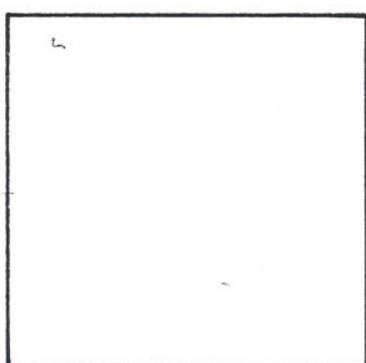
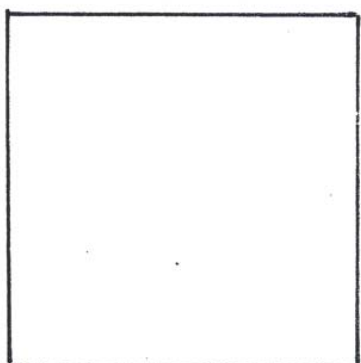
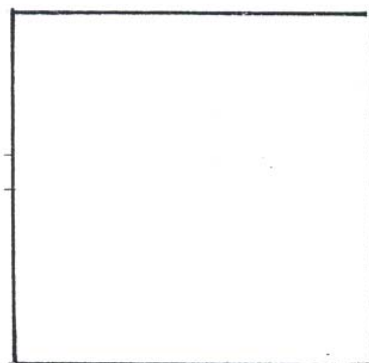
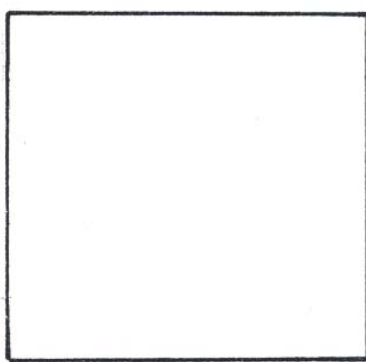
stamp your feet



write it down



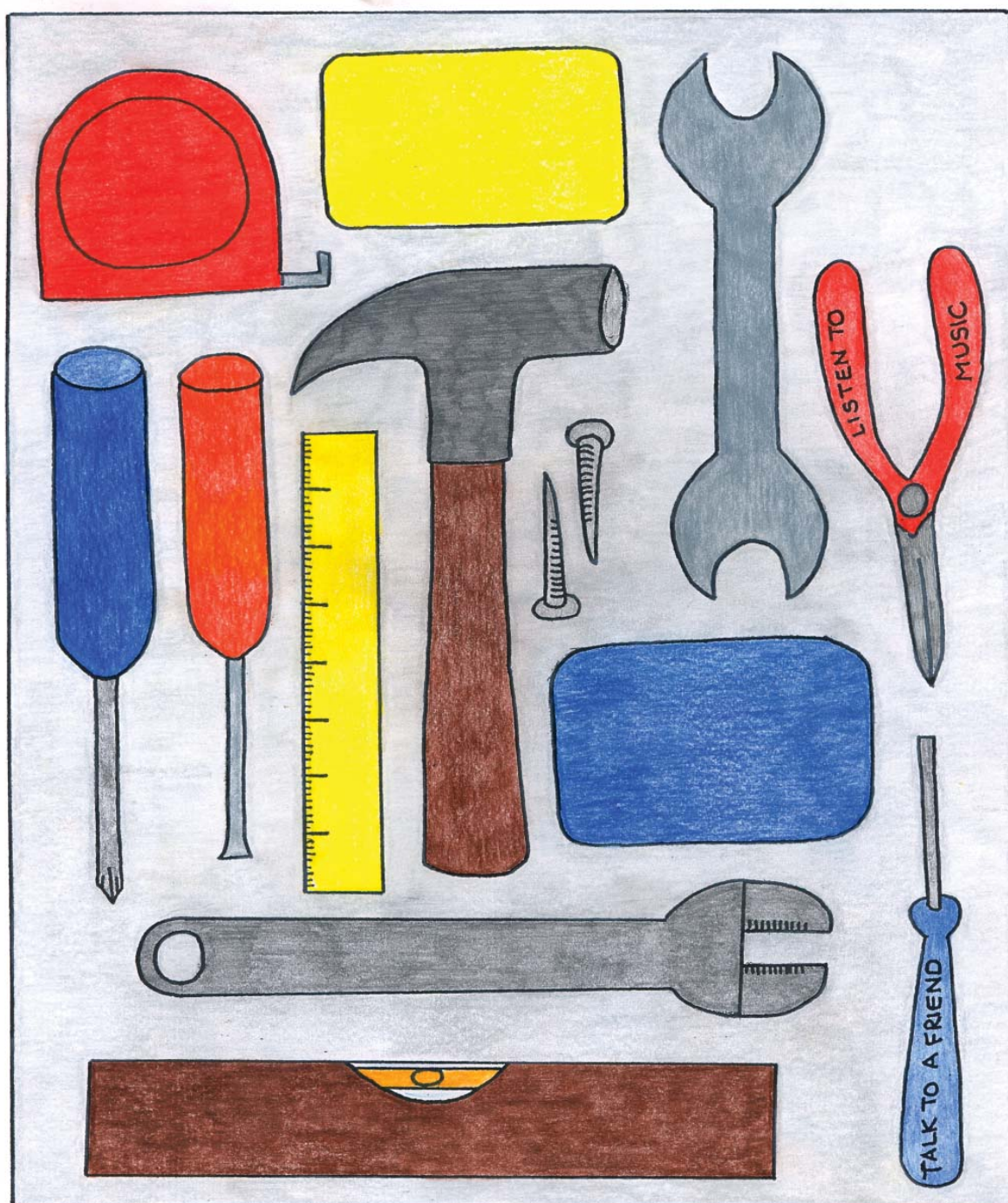
kick a ball

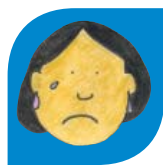




Feeling sad?

This is your imaginary toolkit. You can keep ideas inside of things to do when you're feeling sad. We've put a few in to start you off.





Telling your friends how you feel

If the person with MND lives with you, you might not want your friends to come round to play like they used to.

You may feel embarrassed about the way the person with MND has changed. This may be because of the way they talk or the equipment they use.

Try not to feel too embarrassed. Your best friends will understand if you tell them about MND and explain that the person is just the same as they were inside.

You might want to tell your friends about the person with MND, but don't know where to start. If it's difficult to talk about it, you might want to write them a note instead.

If you like you can use the note on the next page to tell a friend about MND. You might decide to write something different using your own ideas.



Telling your friends how you feel

Dear _____

My _____ has an illness called MND.

The MND makes it difficult for _____

to do some of the things they did before, like _____

_____.

_____ is still the same person underneath.

Sometimes I feel _____

_____ about it.

You could really help me by _____

_____.

Thank you for being a good friend to me.

From _____



Do people die from MND?

Sadly doctors can't make people living with MND better, their body will stop working all together and they will die.

We don't know how long people with MND will live for, as everyone is different. Some people live with MND for many years.

When somebody dies it can be very sad for the people close to them. They might really miss the person, or worry about how they will live without them.

People have different ideas about what happens when someone dies. What do you believe?

Whatever happens, you will always have your memories of the person you were close to and the things you did together.

It's okay to ask questions about dying – you could talk to a grown-up you trust. You might want to contact MND Connect.



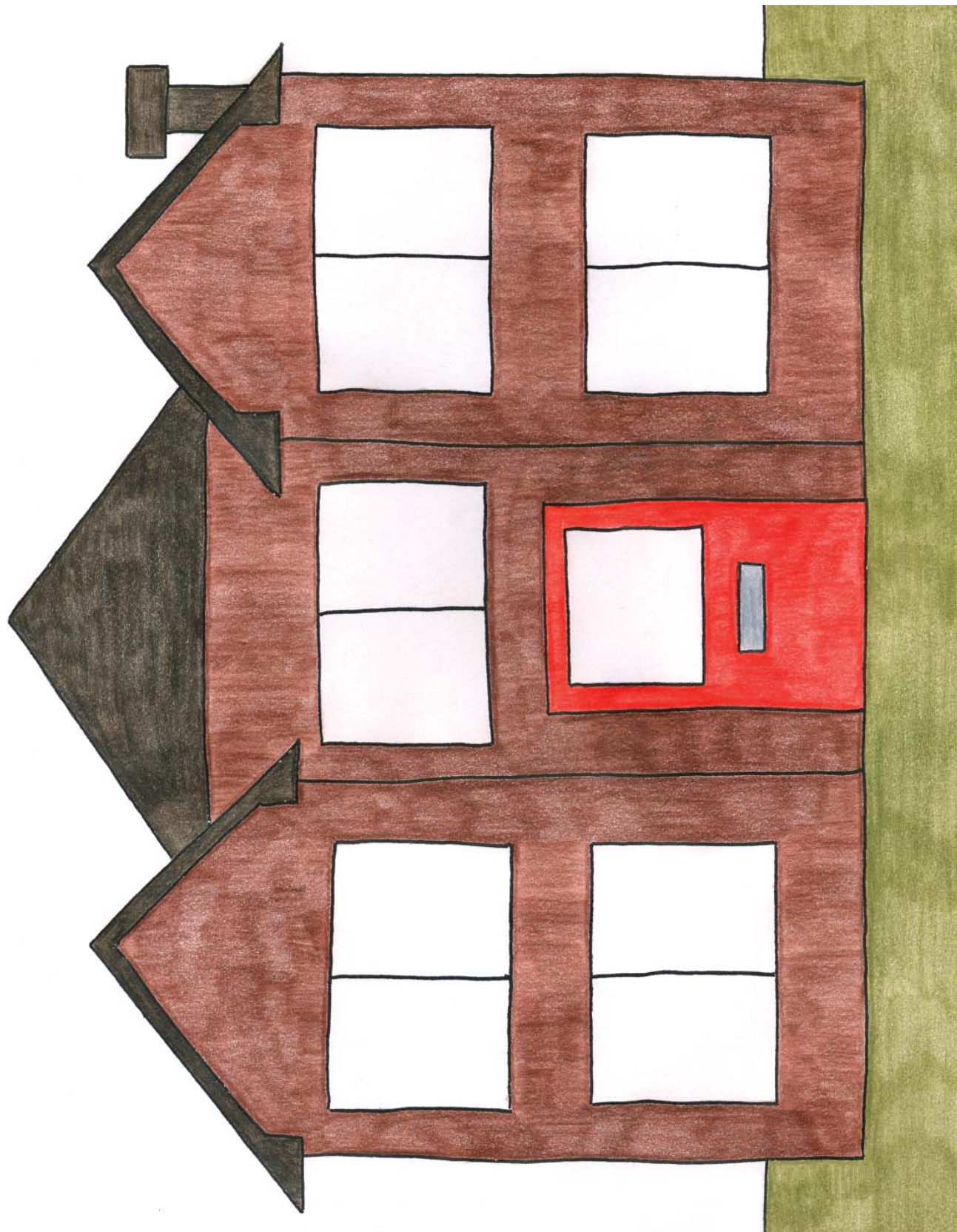
Important people

You might like to use the house picture on the next page.

In the windows you could draw or write the names of people who are important to you.

This might include your family, friends, your teacher, social worker or a nurse that cares for the person living with MND.

If you have any pets, you could draw or write the names of them too.





Asking questions

If you are worried or afraid because you don't know what is going to happen, try not to feel bad, it is very normal that you feel like that.

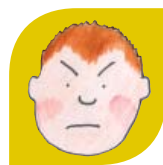
It is okay for you to ask questions.

You might want to ask your mum or dad, aunt or uncle, or another grown-up you trust.

Perhaps you want to let your teacher know how you are feeling too. Your teacher can offer you lots of help and support if they know about what is happening at home.

Asking questions and talking about how you feel is really important. Sharing your worries with someone can often help and even make you feel a little better.

You can contact MND Connect by telephone or email if you need to talk or ask any questions.



Making a question box

You could talk to a grown-up about the idea of making a question box for you to keep.



Every time you are worried about something or have a question to ask, write it down on a piece of paper and post it in your box.

The grown-up could take out your messages and answer them for you or post a reply!





Making a question box

If you think it is a good idea, then why don't you try making your own question box?

You could use an old shoe box or an empty cereal box.

Ask a grown-up to make a slit in the lid.

Decorate it how you like.

You could draw your own design using colouring pens or paints.

You could even cover it in some bright paper.



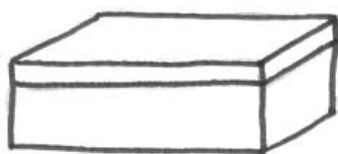


Collecting memories

Making a memory box is a really nice way of keeping all your happy memories in one place.

You can fill it with things that remind you of a person, or special occasions and happy times.

The perfect recipe to make a memory box...



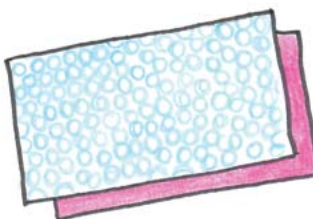
1 old shoe box



Or 1 box file



Colouring pens



Wrapping paper

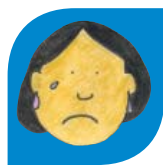


Glue



Glitter

Decorate the shoe box or the box file exactly how you want to...



Collecting memories

Then add lots of memories...

Photographs

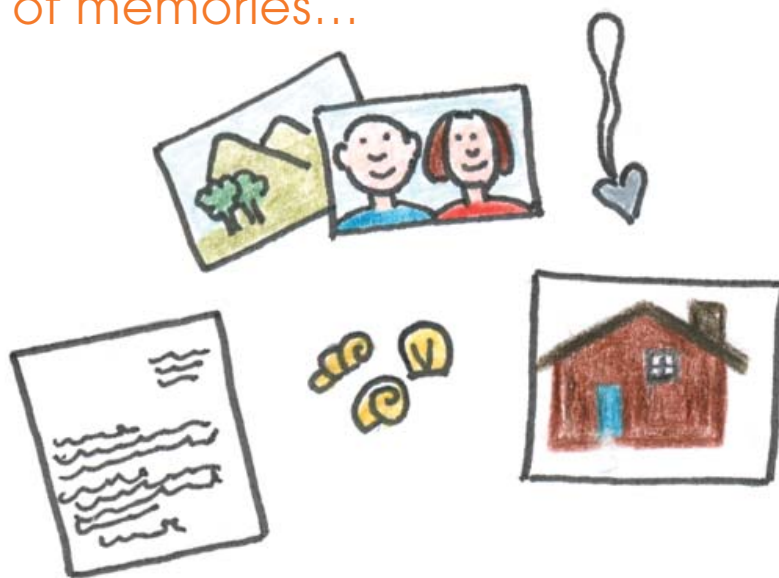
Drawings

Poems

Letters

Shells

Trinkets or other special things





Collecting memories

You could also make a memory book.

The recipe to make a memory book...

1 scrapbook

Then add lots of memories...

Drawings

Letters

Photographs

Poems

Receipts

Tickets



These are just some ideas to get you started with your memory box or book. Perhaps you have some other ideas?



Collecting memories

Special occasions and days out

You can use this page to write about or draw some of the special times you have had.



What do you think?

We would really like you to tell us what you think of the workbook.

Please spend a few minutes answering some simple questions. All you need to do is to circle your answer.

1. Did the workbook help you understand a little more about MND?

Yes

No

A little bit

2. Do you like the way it looks?

Yes

No

A little bit

3. Did you enjoy doing some of the activities in the workbook?

Yes

No

A little bit

4. If you did enjoy the activities, which one's did you enjoy most?

5. Do you want to tell us anything else about what you liked or didn't like about the workbook?

Thank you

When you have filled this in please post it to
MND Connect, Freepost, NH4173, PO Box 246, Northampton NN1 2BR

You don't need a stamp.



Motor Neurone Disease Association

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