FRIENDSHIPS AND ME/CFS

Should I tell my friends what ME/CFS is really like?
Your friends or partner can't know exactly what it's like to have ME/CFS (unless they have it too). So they need you to explain the truth about your ME/CFS to them, so they can understand and support you. If you don't explain, it can lead to misunderstandings and problems - for example, if you have to turn down invitations, or don't have the energy to answer their messages straight away, without knowing or understanding why, they might think you are avoiding them.

But I don't have the energy or confidence to tell my friends
There are various things you can do to help build confidence (see below). Once you begin building your confidence it will take less energy to tell your friends.

Sometimes you will just have to trust your friends to understand and take on board what you are telling them. Placing this trust in others isn't always easy, and unfortunately it's possible that not everyone will understand. This is when you will find out who your real friends are – and some people may surprise you in a good way! If you do lose a few friends, it does hurt, but hopefully with your newfound confidence you will see it as their problem not yours.

To build your confidence, you can try getting in touch with other young people who have ME/CFS (joining AYME will help you do this). This will help you feel you are not alone, and you can share tips on how you all cope with your problems if you want to. It's also a good idea to focus on all the things you've achieved in spite of being ill. Concentrating on your achievements rather than the things ME/CFS prevents you doing can be very uplifting. You can also have counselling - this can help you to be more positive about yourself and give you the confidence to talk about your ME/CFS.

ME/CFS is just another challenge. Not all your problems are caused by your ME/CFS – you may be more normal than you think! Even if you were perfectly well, the chances are there would still be times when you feel embarrassed, shy, nervous, upset, or angry. Everybody has these feelings at times, whether or not they have ME/CFS.

Look at things from your friends' point of view
There's a good chance that your friends will be wondering how to treat you. How do they react to their once-active friend who is now too exhausted even to talk for very long? They could be scared their visit will make you feel worse. They could be worried about whether or not to talk about what they've been up to recently, in case you think they are rubbing it in. People can get scared of what they don't understand, and when they're scared they may try to avoid the issue altogether and stay away. That's why it's important to let them know about your ME/CFS, how you are and how you feel.

But - when you are explaining your illness to your friends, get to the point quickly! They will want to know, but don't bore them to death! Explain that even if you can't see them as much as you used to, you still value their friendship. Don't expect too much from your friends – remember that they still have their own problems to deal with. Give them lots of help and encouragement, and if they stick by you then they are worth their weight in gold.
What if my friends let me down?
Friends lead busy lives (like you did), which might mean that they can't make contact with you for a while. They might make other new friends or they may forget to phone you. Try to understand if your friends need to move on. When circumstances and the things you have in common change, friendships often follow. You might find you need some friends who have ME/CFS; your old friends might need to make new friends who can still go clubbing. It doesn’t mean you can’t be friends any more, it just means that the friendship will change. When you think back, you may well have gained and lost friends before in the past for other reasons, perhaps changing schools or moving home. The really good friends are still in your life despite those changes (although maybe in a different way from before); others will have faded more into the background.

If you do break up with your friends, you are bound to feel upset, let down and angry, but life is too short to hold grudges, especially when you have ME/CFS. Stress, worry and regret are bad for your health, so forgiving your friends and moving on is hugely important, even though it may be hard on your pride.

I’m a severely affected member (SAM), what about me?
Friendships for people with severe ME/CFS are not always easy. Your friends may find it hard to understand that you are too ill for them to visit or talk to. The severity of your symptoms may scare them. SAMs often have to rely on family members to help maintain those friendships.

If you are too ill to email or text your friends, or to talk on the phone, you could dictate your messages to a carer who could send them for you. You could send the same email round to lots of your friends, or speak into an audiotape if you can and send that.

It is very hard not to overdo things when your friends do visit. Using a timer that goes off when the time’s up means that neither of you has to actually say it. Friends could visit you for a short while, chat with the rest of the family while you take a rest, then visit you again before they leave. If you can’t hold a conversation, your friend could bring a book with them or something else to do – they need to know that it’s nice them just being there to sit with you, even if you can’t talk to them. Unfortunately some friends will just be unable to cope with how ill you are and may not want to stay in touch. This is hard to come to terms with.

AYME runs a special group for SAMs including a buddy scheme for severely affected members where other AYME members write regular cheery letters and cards to SAMs without expecting a reply.

What about when I have to be on my own?
Loneliness and ME/CFS is a mighty combination. It’s helpful to try to learn to enjoy your own company. Accepting your situation (for now) is the first step to happiness. Planning to do activities little and often, rather than all in one go, helps beat boredom and is far better for your health. If you can do an activity for, say, 15 minutes, then rest for the remainder of the hour, that will spread your activity out all day, and gives you recovery time in between so that you don’t feel ill for days afterwards. Over time you may find you are able to extend the 15 minutes and feel a real sense of achievement. There are loads of other suggestions for pacing for SAMs in the AYME book *Surviving Severe ME*.
I’m a bloke, what about me?
Friendships can be even harder for blokes because they chat less and hide their feelings more. Male friends care, but don’t know how to show it and don’t make contact. At times you may feel very isolated; but try to have a bit of confidence and make an effort to continue relationships or speak up-front about your illness. If you don’t, you may end up feeling stranded. It can help to have friends outside school or college – you can dip in and out of these and just pick up where you left off. Friends from school can tend to carry on with their own lives and drift away. Contact other blokes through the AYME message board - life-long friendships have started there.

How can my family help?
Your relationship with your family is important and it is hard to cope with the difficult times if you feel they are unsupportive. Remember though, that parents and brothers and sisters are human too. They might find your illness distressing, pretend that it isn’t happening, or be unable to face up to the effect it is having on your life. If there are other problems in the family they might seem insensitive to the hurt you are feeling. They will need your understanding as much as you need theirs.

On the other hand, your family may be very supportive and help you maintain your friendships. However, they shouldn’t be over-protective and should realise that although seeing friends sometimes wears you out, it’s worth it. You need to explain that you take your friendships seriously and that you need their help. You need to know they believe you when you say that you are too ill to do something that has been planned. Give them a chance – be honest and let them know how you are feeling and how much you appreciate their love and care.

New ME/CFS friends – are they ‘proper’ friends?
Having friends that understand what it’s like to live with ME/CFS can keep you from going completely round the bend. Becoming friends because you’ve got ME/CFS doesn’t mean that you aren’t proper friends – it’s the same as making friends because you’ve joined a new social club or taken up a new hobby. The important thing to remember is that you are friends because you get on with each other. A friendship is something to treasure, whether the friend has ME/CFS or not. Relax and enjoy it!

What about if my ME/CFS friends are only online and I don’t actually see them?
They can still be real friends, and although you don’t see each other, you probably understand each other better than most, which means you can connect in very important ways. In fact, research by University College, London in 2005 found that using websites with chat rooms or message boards can help people with long-term health conditions; and as well as feeling better informed and supported, overall most could see an improvement in the way they looked after their health and managed their condition. So online friends are definitely worth having!

The AYME website has a members-only message board for young people with ME/CFS plus a message board for parents on its sister site www.aymelink.org.uk. There is also a group called Grads for people who have reached 26 but love what AYME has to offer.
Are any friendships bad for me?
No, but try not to become dependent on just one friend, whether they have ME/CFS or not. There is a danger that you will exclude everyone else at the expense of that friend, or that you will be devastated if the friendship ends.

Be open-minded about whom to have as friends. Your parents' friends could turn out to be good company during the day when your own friends are at school or college. Your parents' friends' children might also be worth checking out. Even your brother or sister might be worth a look!

Tips for making and keeping friends

• If you're up to it, try to phone or text someone at least once a week – make it part of your activity diary.
• If you can get online, use the AYME message board or chat room, use email, or get in touch with other members and give them some support – they may need it too.
• Try to make sure that you have a few ME/CFS friends. That way you'll have friends whom you don't have to talk ME/CFS with, because you know they know all about it.
• Become your own social secretary. Healthy friends may be unsure of your limitations, so if you make all the arrangements they know that you want to see them and you know the visit will be within your personal boundaries (be aware of how tiring the planning can be).
• Plan the visit. Let your friend know beforehand how long they can visit for. You could also mention some stuff that you'd like to talk or hear about – your friend won't worry then about what they're going to say.
• Have your family pet in the room when your friend comes round. It gives them an alternative focus so they don't stare at you all the time!
• Arrange a video night round your house. You can lie on the sofa and watch the film, and so can your friends.
• If you're well enough, see if there is an evening course or workshop that you can go to. You will meet new people who have the same interest as you.
• When you're well enough to go back to school or college or to join a social club, think about going somewhere new, rather than returning to the place where everyone expects you to be exactly the same person you were before you got ill (memories can be quite upsetting).

What if I'm the friend of someone with ME/CFS?

Be yourself! Act normally – your friend is still the same person underneath their exhaustion and weakness. They are still interested in the same things, still thinking about their other friends and still want to be your friend. At the same time, don't pretend the ME/CFS isn't there. Consider your friend's new needs – if you don't know what they are don't guess or assume – ask them! Make a pact to be open and honest with each other so that you both know where you stand. If you're unsure about something you must be able to ask, and if your friend feels unwell they must be able to tell you.

Try to listen to your friend, understand their limitations and learn from it. If you are out with your friend and you ask them if they're okay, they might say they are 'fine' because they don't want to be a nuisance to you. So rather than asking them how they are, try to be more specific and ask things such as whether they're ok with the crowds or the noise, or if they would like a rest. They might say 'yes', which you wouldn't have known otherwise. And remember friendship still works both ways – if you've got a problem, you can still ask your friend for their advice. They may have ME/CFS, but they haven't stopped caring (just don't go on about it for hours!)
Don’t desert your friend just because they can’t take part in things like they used to. A quick text or phone call to say hello will be appreciated. Even if your friend can’t use the phone, knowing someone called can make a huge difference. Offer to pop round for a short while in the evening if your friend can take it. If not, try again another time, but keep offering. Try not to take offence if your friend can’t see you. And if your friend is well enough, plan an evening in with friends, or just you at the home of your ME/CFS friend. Host the evening yourself so that you do all the work and your friend doesn’t have to. You can choose different themes to keep it interesting.

Don’t feel guilty about not staying for hours and hours; your friend will be glad of your company but might also tire quickly. Remember, you can’t rely on your friend letting you know when they’ve had enough – they’re likely to put on a brave face for your benefit. It’s ok to talk about things you’ve done because your friend can’t do them any more. Your friend will want to hear what’s going on in your life. Even if you think you’ve been doing nothing, it’s likely to be more than your friend with ME/CFS has done, so they will be interested to hear about it. You can talk about everyday things such as school and shopping, cinema, other friends, holidays, etc. Take photos of people at school, outings your friend couldn’t go on, etc. and take them with you when you visit. Your friend will enjoy being included in these things even though they can’t actually be there.

It’s said that people come into your life for a reason, a season, or a lifetime
When someone is in your life for a **reason**, they will be there to meet a need you have, or maybe help you through a difficult time. This help could be deliberate on their part or accidental (perhaps someone who is there to test your commitment or patience). Either way, once their time helping you is over, something will happen to bring your relationship to an end. Sometimes they quietly fade out of your life. Sometimes they walk away. Sometimes they force you to take a stand. Whatever happens, your need has been met, and their work is done. It is now time to move on.
When people come into your life for a **season**, it is because they have something to offer you, and your turn has come to share, grow, or learn. They may bring you an experience of peace, or make you laugh. They may teach you something you have never done. They usually give you an unbelievable amount of joy. But only for a season in your life.

The people who are with you for a **lifetime** stick with you through reasons and seasons. Lifetime relationships teach you lifetime lessons and help you build a solid emotional foundation. Accept the lessons, love the person/people; and acknowledge, value and be thankful for the people who are with lifetime friends.