Information for relatives and friends

Inpatient Services

COTSWOLD HOUSE
SPECIALIST EATING DISORDERS

Information for relatives and friends

Why read this leaflet?

The aim of this leaflet is to prepare you for what you might experience and we hope it will be of some help in addressing your concerns.

Your right as a family member carer:

Under guidance in working with families you are entitled to information about the illness, treatment options and what to do in a crisis. You are also entitled to information regarding support for yourself and other family members, information about Carers Assessments and information on other organisations that may be of help. If the person you are supporting consents to their treatment information and progress being shared with you, you can have an active role in CPA's, care planning and discharge planning. If the person you are supporting does not consent to information being shared you can still share your views about treatment but progress/options may not be shared with you. You always have the right to be listened to.

What are eating disorders?

The National Institute of Health and Clinical Excellence (NICE) guidelines on eating disorders showed that 1.6million people in the UK were affected by eating disorders in 2004 and 180,000 (11 per cent) of them were men and only the most serious cases are hospitalised. In 2007 the NHS Information Centre carried out a snapshot survey of people in England over the age of 16. It found that an alarming 6.4 per cent of adults had a problem with food, a figure much higher than previously thought. A quarter of this figure was men suggesting a possible increase in the number of males affected. Individuals with anorexia and bulimia are preoccupied with controlling their weight and shape by restricting the food they eat. In the case of bulimia and sometimes anorexia, people also binge on food in an out of control way that they then might compensate for by vomiting, over-exercising or using laxatives.

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If you need the information in another language or format, please ask us:-

Bulimia

Bulimia Nervosa and Binge Eating: A Guide to Recovery. P.J. Cooper (1995) Robinson.

Getting Better Bit(e) by Bit(e). U. Schmidt and J. Treasure (1993). Lawrence Erlbaum Associates Ltd. (1995). Guildford Press.

Eating Your Heart Out. J. Buckroyd (1994) Optima.

Other

Overcoming Low Self-Esteem. M. Fennell (1999). Robinson.

The Dance of Anger. H.G Lerner (1989) PerennialLibrary.

The Dance of Intimacy. H.G Lerner (1989) Perennial Library.

Diet Breaking: Having it All Without Having to Diet. Mary Evans Young (1995). Hodder & Stoughton.

Fear of Food. Genevieve Blais (1995). Bloomsbury.

The Secrets of Self-Esteem. Patricia Cleghorn (1996). HarperCollins.

My Body, My Enemy. Claire Beeken. (2000) HarperCollins.

The Body Image Workbook (2nd edition). T Cash (2008) New Harbinger Publications.

Eating disorders can usually be seen as an attempted solution to underlying problems. For example, eating disorders can develop as a way of coping with emotional distress or as a way of communicating feelings to the external world and exerting control over it, especially when someone's internal world feels very much out of control. This can begin to help us understand why it is so difficult and often terrifying for the individual to give the eating disorder up. Eating disorders are therefore much more complicated than having difficulties eating food and the problems are rarely solved just by re-learning normal eating and maintaining a healthy weight.

What is Cotswold House Specialist Eating Disorders Service

Cotswold House Specialist Eating Disorders Service is a multi-disciplinary service for individuals aged over 17 with severe eating disorders, i.e. The service is aimed at people that are severely underweight or severely bulimic, who have usually had their disorder for a long time and have not responded well to previous forms of treatment or have suffered rapid weight loss. The service is part of Oxford Health NHS Foundation Trust. We see patients, their families and carers from Oxfordshire, Buckinghamshire, Bedfordshire and other areas. We are a multi-disciplinary team consisting of clinical psychologists, consultant psychiatrists, clinical nurse specialists, occupational therapists, nurses, support workers, a dietician, a family therapist a social worker and admin team. We aim to provide a specialist service that can offer inpatient, day patient and outpatient treatment. An important strength of our service is that individuals can move easily between inpatient, day patient and outpatient care whilst retaining contact with the same individual therapist and treatment team. In our experience this offers the long-term stability necessary to support full recovery from an eating disorder. For those who live out of area, there is a careful handover from the ward therapist to the local team therapist.

The Inpatient Ward

The Health and Social Care Information Centre (HSCIC) has released figures on 11th October 2012 showing hospitals in England recorded 2,290 eating disorder admissions in the 12 months to June 2012; a 16% rise on the previous 12 months. The report also shows: Children and teenagers aged 10 – 19 accounted for more than half of admissions. The biggest numbers of admissions were for 15 year old girls. Women accounted for 91% of all eating disorder admissions.

Anorexia accounted for 74% of all admissions. A recent report from the Royal College of Practitioners has indicated a 66 per cent rise of male hospital admissions. The inpatient ward has 14 beds. We aim to provide 24 hour care and support for people who are extremely underweight or show severe eating disordered behaviours, as well as those who feel that they would benefit from such intensive support. All meals are provided and inpatients also take part in the groups that make up the Group Programme as deemed appropriate. If you are concerned about your relative or friend you can ring the ward on 0186 738844/45 and ask for the nurse in charge who will help you with general queries. Since we are an adult service we must maintain patient confidentiality and cannot is disclose any specific information about patients without their permission. However each patient is allocated a designated worker who will make contact with carers. The designated worker will explain to the patient that it is our duty to give generic information to carers/support network and that we can listen but will not share specific treatment information without consent. A designated worker will make contact with carers within 72 hours of admission.

At your first meeting with your designated worker, the below information will be given to you and discussed:

- Carers Guide to Cotswold House
- Explanation about Friends & Family Group and family workshops
- Confidentiality
- Role of designated worker
- How to get support – signposted to support section in Carers Guide

Useful References

Advice for Carers

Overcoming Binge Eating. C. Fairburn.

A Carer's Guide: A Practical Guide For Carers of People with an Eating Disorder. (2000) Eating Disorders Association.

Eating Disorders: A Parents' Guide R. Bryant-Waugh, B. Lask (1999) Penguin

The Shelter of Each Other. M. Pipher (1996) Ballantine Books.

Skills-based Learning and Caring for a Loved one with an Eating Disorder. J Treasure et al (2007) Routledge

Anorexia

Anorexia Nervosa: A Survival Guide for Families, Friends and Sufferers. J. Treasure (1997). Psychology Press.

Anorexia Nervosa: The Wish to Change. A.H Crisp, N. Joughin, C. Bowyer (1996). Psychology Press.

Anorexia Nervosa: Let Me Be. A.H Crisp (1995). Lawrence Erlbaum Associates Ltd.

Anorexia Nervosa: A Guide to Recovery. L. Hall, M. Ostroff (1999). Gurze Books.

Overcoming Anorexia Nervosa. C. Freeman (2002). Robinson.

The Anorexia Workbook: How to accept yourself, heal your suffering and reclaim your life. M. Heffner and G. Eifert (2004) New Harbinger Publications.

Making Weight: Men's Confl ict with Food, Weight and Appearance. A. Anderson et al. (2000). Gurze Books.

Complaints procedure

If you are unhappy about some aspect of our service please feel free to approach a member of staff who will explain the complaints procedure to you. Alternatively, you may wish to telephone or write to our Associate Clinical Director, Nicky Boughton, who can be contacted at Cotswold House Oxford.

Other resources:

Carer's Trust

Carers support is a national organization that supports anyone is a caring role, they usually have a specific Mental Health Support Worker and can give you support regarding your caring role and can inform you of your rights and anything you may be entitled to. You can usually access pampering sessions, days out and support groups.
Their website: http://www.carers.org/
On the website there is an option to find your local office.

More on your rights as a carer can be found here:
http://www.direct.gov.uk/en/CaringForSomeone/CarersRights/index.htm

If it is not possible to have a meeting with you in person the conversation will need to take place via telephone and the information posted. We encourage family and friends to stay in contact with their friend or relative whilst they are inpatients here. Mobile phones are allowed on the ward or you can contact them on the inpatient telephone number 01865 738894.

Visiting

You are also welcome to visit any evening between 16.30pm-18.00pm and 19.00pm -20.30pm visiting is more flexible at the weekends. Please ask the nurse in charge for further details.

Patients are made aware that the following Items are not allowed on the ward

Please do not bring these items in for them:
Laxatives-may support eating disordered thinking and behaviour
Alcohol-can worsen depressive symptoms, lower inhibitions (can lead to binging and self harming behaviours)
Fizzy drinks-these can be used to suppress appetite
Chewing gum-these can be used to suppress appetite
Diet medication- can support eating disordered behaviour and thinking
Illicit drugs-mood altering and lower inhibitions
Food-no food allowed other than meal plan items, this is to discourage binging.

A note on the Mental Health Act:

The Mental Health Act (1983) allows for the detention and treatment of individuals suffering from a mental illness. The individual must be seen to be posing a risk to either themselves or others to be assessed and detained. Within the context of eating disorders the risk is usually in regard to physical health and that if treatment is not commenced it could be life threatening. If a patient is medically stable and can show capacity (ability to make informed decisions about treatment, demonstrating ability to weigh up costs and benefits of treatment) then The Mental Health Act cannot be used. This can be frustrating for families as you may feel things will deteriorate again and that current weight will not be maintained, however, The Human Rights Act overrides The Mental Health Act (1983).

Person's goal: stabilisation or recovery

There is an expectation that patients will gain approximately 0.5-1kg per week. Weight gain is done in a careful way through the dietician to avoid re-feeding syndrome. This can occur as a result of food being reintroduced to the body after periods of starvation. Re-nourishing the body is traumatic for the body and person experiencing it. Patients can experience oedema (water retention), colicky symptoms, fluctuating body temperatures, nausea and intense mood swings.

Full recovery: Cotswold House encourages and advocates that all patients aim for full recovery from their admission. Full recovery consists of reaching a healthy BMI of 18.5+ and re-establishing a balanced life, which would include a maintenance meal plan, a moderate amount of physical activity and regaining a sense of normality through activities away from the ward.

Stabilisation: Some patients enter Cotswold House and do not feel ready to aim for full recovery. For these patients, stabilisation is the aim of their admission. Stabilisation is where the patient works toward reaching an agreed BMI that is below what is considered healthy and normal, but means that they are medically stable enough to be discharged. If patients choose to maintain lower than a healthy BMI range a maintenance meal plan may be introduced when it is deemed safe to do so. Discharge would then be discussed and planned after two weeks of maintaining at Cotswold House.

Physical Activity

Cotswold House has specific activity guidelines (see separate handout) to ensure a safe level of activity. The decision to increase a patient's activity level is dependent on medical state and their ability to manage and comply with treatment. However, for the first week it is expected that all patients remain on the ward – irrespective of their BMI. Initially, activity restrictions are designed and put in place purely to minimize medical risk. Bed-rest and the use of wheelchairs will be avoided wherever possible, but may be necessary as a short-term measure for patients with very low BMI's. Activity levels are designed to enable

present a variety of topics. The group is open to individuals regardless of whether their loved one is a patient within the service or not. It is an open group and people can attend on a flexible basis.

One day Family and Carer workshops specifically for addressing Eating Disorders

Please ask the ward for future dates and details these workshops serve all Oxford and Bucks Eating Disorder services numbers are limited please ask for your name to be added to the list to guarantee your place.

Carers Assessments

A Carers Assessment is your one legal right as a carer. It involves individual time with you talking through your caring role and seeing if anything can be done to support you.

More information about Carers Assessments can be found here:
http://www.nhs.uk/CarersDirect/guide/assessments/Pages/Carersassessments.aspx

Lastly…

We hope this leaflet has been useful to you. From time to time you may have questions or concerns that have not been addressed here. You should feel free to approach any member of our staff team for help. Alternatively, you may find it useful to contact your local Eating Disorders Association, beat, who provide excellent support and advice to sufferers and carers. The national help line number is 0845 634 1414.

Take care of yourself too

People develop eating disorders for many complicated reasons. You may find it difficult not to feel responsible but blaming yourself does not help you or the person with the disorder. Worrying and looking after someone else can be emotionally draining. You cannot expect to be strong all the time. It is human to feel angry and exasperated and express this frustration at times. Keep up your social life and interests. It is important that you try to get on with your own life as much as possible, such as going away on holiday. If a person sees that normal life has broken down for their friends and relatives they may blame themselves, which will add to their feelings of low self-worth. Try to acknowledge and accept these feelings openly with the individual and try to focus on the healthy and good things about your friend or relative. Your relative or friend may want to care for you to compensate for all the worry they have caused you. Try not to encourage this because it is important that they look after their own physical or emotional needs. Therefore they are not the best person to look after your needs. As often as you can, try and show them you love them regardless of their weight or achievements. Use physical affection if you want to, pay compliments about aspects of their personality or interests but not their appearance. If they ask about the way they look, let them know gently that you will talk about anything except calories, appearance or weight.

Family and Friends Group

We recognise that friends and family can be left with the illness 24/7 and often don't speak to other people for support due to stigma and often carry a burden of blame and guilt. Although you might understand that an eating disorder is an illness you may think that you can or should be able to prevent it from happening. You might have been excluded from previous care settings and left feeling blamed. It is important that you ask for help when you need it. You may look for support among friends, family or a relatives group (to meet people who are in a similar situation to you), or you may seek specific relationship counselling. We run a Friends and Family group at Cotswold House which meets monthly on a Saturday (10:45am to 12:30pm). If you are interested in coming, please ask our secretary for details. The purpose of the Family and Friends group is to offer support, advice and help and to provide an opportunity for you to talk with others who are experiencing similar difficulties. It is facilitated by experienced staff and a programme is designed to

patients to gain weight at the required rate per week, whilst also promoting wellbeing and aiding a 'normal' redistribution of body weight. Patients are encouraged to avoid any aerobic activity until their BMI is approaching target range (generally above 18.5). Advice will be given to patients regarding suitable exercise.

What role leave plays in treatment?

During their time at Cotswold House, patients are encouraged to take therapeutic leave as part of their treatment and discharge planning process. Therapeutic leave allows the patient to be able to practise what they have learnt on the ward and transfer those skills back to a home setting to see how they will manage at home on a day to day basis following discharge. They can utilise the new skills they have learnt on the ward during leave, for example, serving their own food, preparing their own food, food shopping etc. It is not expected to go smoothly as first, with practice however, the expectation is that patients will be able to manage a meal plan, remain in their weight band and repeat any individual food preparation work they have been practicing on the ward. Patients need to request home leave in the weekly ward round on a Monday. If they plan to stay with family patients are expected to prepare with their care team and family to discuss meal planning, activity levels and any other concerns that you may expect to encounter. Their request will be discussed and agreed by the Cotswold House team. Leave will be granted by the team based on whether or not the patient is medically stable and fits the necessary criteria (based on the BMI guidelines). It is advised that patients take home leave over the weekend in order to avoid interruption to the group programme. The patient is responsible for sorting out transport; usually this involves asking family or using public transport.

Before leave

When requesting their leave, patients will need to ensure that they have arranged suitable transport for getting to and from home. The team advise that ideally patients are transported by a relative or carer to and from the hospital to home. Patients will need to plan a food diary which they will complete while on leave. They can plan this with the

dietician or with someone from their care team. Patients will also need to discuss their plans for food shopping, activity levels and any other concerns they think they may have while at home. Staff will arrange for the patient to be written up for medication that they can take home with them; these are called TTO's.

What can you do?

It is a good idea to establish with the patient how they would like to be supported by you while at home. In the following sections titled "things to consider", we provide you with a list of items you may need to address with them and/or their care team. You may want to liaise with a member of their care team (preferably their designated worker on the nursing team) prior to home leave commencing, so they can address any concerns or answer any questions you may have. Please call the ward to arrange this ahead of time. You are welcome to get involved in the planning of home leave this with them and their care team if they are happy for you to do so. You can request literature on the medication they are currently taking, including information on side effects etc. This can be provided by their care team or the pharmacist for the ward.

Tools to assist with leave

Patients and carers may find it helpful to take the following resources home with them to which they can refer:

- A copy of their current meal plan
- A copy of the recommended portion guidelines
- A copy of the activity guidelines
- Their food diary for the leave period

During leave

Meals

We expect patients to eat 3 meals and 3 snacks per day while in treatment. This includes breakfast, AM snack, lunch, PM snack, dinner and an evening snack. You may need to consider whether or not they will require prompting to have their meals. It is worth discussing if and when they

What about rituals around eating?

You may notice that the person with the eating disorder eats in a specific way; they may use a special plate, have a particular seating position, cut their food into very small pieces, have rigid meal times, or take a long time to eat a meal. Some of these behaviours will be more disruptive to your life than others. The best thing to do is to decide which ones affect you most directly, talk about these openly and negotiate changes whilst recognising that there may be some that you need to tolerate for now.

Should I let my own feelings show?

You may feel under pressure to say and do the right thing. It is not uncommon to feel controlled by someone with an eating disorder and this can make you feel resentful or frustrated. Don't ignore these perfectly natural feelings but try to talk about them instead. It will be easier to avoid conflict if you talk about how your friend or relative's behaviour affects you. For example, 'I worry when you over-exercise because I know this can be dangerous for your health', as opposed to, 'you are causing everyone so much worry with your exercising'. This lets them know how their behaviour affects others while not adding to their guilt. Try as much as you can to have normal conversations with your friend or relative. This will help them to understand that you are interested in them as a person and in their opinions, not just in the eating disorder. It is a brave step to give up an eating disorder so you can help by praising even the slightest progress and be supportive even when they have taken a backward step. An important part of recovery is knowing how to manage more challenging days. It is not uncommon to see displays of anger, which may be quite shocking but are not necessarily a bad sign. The eating disorder may have been a way to avoid and manage intense feelings that have been blocked out for months or even years. So these angry outbursts may well be a step forward to highlighting issues that need to be explored further. It can be useful to try and remember that your friend or relative is in the grip of something that has control over them. It may help to think that they are experiencing two conflicting voices – the eating disordered voice which is loud and strong and the healthy voice which is small and quieter. Resistance to change and help are integral parts of the condition. Your relative or friend is not being deliberately difficult; their resistance is a reflection of their fears.

any changes, no matter how small, and recognise that any change may be an important shift. However, it is also important to accept that the sufferer may be unable to stop bingeing at the present time.

How should you respond to self-harm?

This may be distressing for you to cope with or understand. If a person is self-harming this will be addressed as part of their treatment. A common reason why someone self-harms, often by cutting, hitting or burning, is to release tension or punish themselves. Although it is difficult, try not to let your feelings stop you from talking about it. Again, you may not be able to stop these behaviours but you may learn how to comfort your friend or relative before and after the event. Ask your relative or friend what they have agreed with us regarding self-harm and about coping strategies they may have discussed with their individual therapist.

What is the best way to manage meal times?

It is difficult to be specific because each person's needs are different. Some people may want to eat with family or friends and others may not want to burden them or feel unable to use the support of others so therefore prefer to cook and eat separately. We actively discourage diet products but understand that these feel safer and may initially enable people to eat on their own, away from the ward. The important thing is to discuss issues around food and shopping, and to understand the distress that food can cause someone with an eating disorder. You could ask how you can help the person before, during or after mealtimes. In our experience we have found it is best to have such conversations before or after eating, not during. It can also be useful to discuss social events that would involve eating in front of other people. These situations are often seen as very stressful for an individual with an eating disorder and you can help by discussing what feels realistic for them and by offering your support for whatever they decide. An eating disorder can often prevent people from enjoying social eating and you can help by making them feel welcome to be involved whilst at the same time avoiding the pressure of eating exactly the same as other people. During the meal keep to topics of conversation that do not focus on food; what you have done together, TV programmes. This will help to distract the person from fears about eating the meal.

would like to be prompted. You may want to discuss if and how they would like to be challenged when eating, e.g. if they are secreting food, not completing etc. Some people like to be gently challenged during the meal, some like to talk about this after the meal. You also may need to plan ahead for meal times. For example, if you are planning an activity away from the home you may need to take a snack with you for them to eat if you think obtaining one while out may be difficult.

Food Preparation

Patients are expected to eat similar portions and similar foods to that of the ward whilst on home leave. For example, patients are encouraged to eat a variety of snacks such as crisps, chocolate bars, biscuits and cakes. For their meals, patients should stick to the food portion guidelines and should be including all the elements of food into their meals. If patients are in the process of learning to prepare food for themselves on the ward, it is important that they use their leave as an opportunity to practise this. If they are not yet ready to prepare food for themselves you may be required to prepare it for them. You can seek guidance for this from staff and it is helpful to use the tools detailed above. If they are preparing and serving their own food they may require support for this, if they so wish. You may need to help them ensure they are using the correct amount of food and are following their meal plan etc. They may also require support from you to go food shopping or to buy ingredients. Some people may prefer that food is bought-in in preparation for them going on home leave. This is something that can be planned before home leave commences.

Activity Levels

Patients are expected to maintain activity levels similar to that on the ward and to complete rest periods as per ward guidelines. If patients are going to be engaging in more activity than they would on the ward we would advise that their food intake accounts for this. More detailed leaflets are available on request to guide you on this and you may want to refer to the activity guidelines and where they are with their activity allowance at the time. You may feel that they are doing more than they should be. In this case you can either challenge them on this or this can be something that is addressed after leave with staff.

After leave

Patients will need to hand in their completed food diaries to staff who can then review them at the following ward round meeting. Staff will talk to the patient about how home leave has gone and identify any issues that may need addressing in light of the next home leave. On return to the ward staff may request a brief chat with you to talk about how you feel the leave has gone. It is beneficial for staff to receive feedback on how the leave has gone, and staff can offer you support and advice around this, addressing areas that went well and that may need improving.

FAQ

Do we have to eat what they eat?

It is a good idea to ask them what they would find most supportive. They tend to feedback that at the early stages of their treatment they find it most helpful for families to eat at the same time as them and generally eat the same food. If you really do not want to or cannot eat the same as them it may be helpful to at least eat something or have a drink at the same time as them for support.

But I'm on a diet, how can I eat the same?

You need to remember that you have not got an eating disorder and that you are therefore able to eat what you want. However, it is important to be mindful of your conversation around this in front of them. Generally conversations about weight, dieting, calories, exercise etc. are unhelpful and at times, triggering, for them.

What if they don't eat?

Do not panic! Usually they are only on home leave for a short time and we don't expect it to go perfectly. When they return to the ward we can address the issues they had and get them back into the routine of eating. The best thing you can do in this situation is to continue to model normal eating, gently prompt them to eat at meal times in a supportive way and if you need to you can telephone the ward for support.

Pre-action: they are thinking about making a change and are thinking about how this could happen. If someone is at this stage you can help them think about what will be difficult and obstacles they will have to over-come, e.g. if you want to start a job how will you deal with questions about your illness if you are asked?

Action: thank goodness! You can help by praising what they are doing and be prepared to see the small steps.

Maintenance: is the last phase and the most difficult. You can help by not letting a relapse turn into a collapse. Reminding them of their coping strat-egies will be helpful, as will having a relapse prevention plan in place.

In short we cannot force, cheerlead or convince someone to change, this needs to come from them. It is helpful to think about what stage they are at so we don't take too much responsibility for them being in the right place.

Specific questions we are often asked

How should you respond to over-exercising?

It is always best to be open about what you have noticed. Try not to be critical because the person may feel driven to exercise and have little sense of control. Let them know that you are aware that they are over-exercising and that this is dangerous. Try to find out why they feel the need to exercise to show that you want to support them and want to un-derstand their viewpoint.

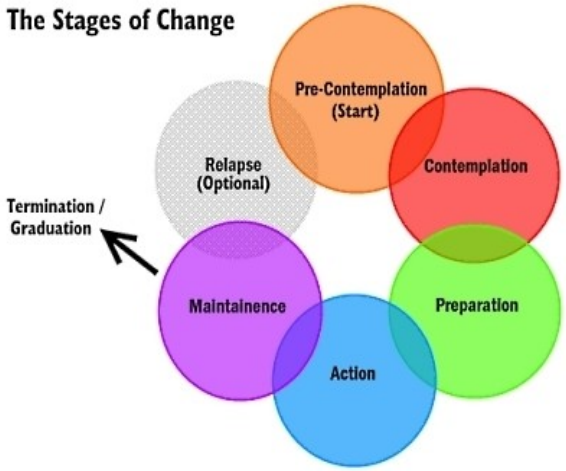
How should you respond to bingeing?

If you lock or hide food at home without prior agreement the sufferer will probably feel resentful and obtain it from somewhere else. Instead ask how you can help and together you may be able to come up with strate-gies to reduce the bingeing. Find out when the sufferer is most vulnerable to bingeing (e.g. when they are upset) and suggest distraction such as going for a walk together. This will help manage the urge to binge and also make them feel less isolated with their problem. Try to notice and praise

Understanding Change

Changing any behaviour is difficult, for example think about the time you tried to go to the gym more often, keep more on top of the housework, stopped smoking etc. For someone with an eating disorder we are asking them to change their current ways of coping and try new ones. Due to the strength of eating disorders, asking someone to give it up their illness is similar to asking someone to give up a child. If we can understand what happens when people consider change we can support it better.

Stages of change:



Pre-contemplation: they will not think there is a problem, be in denial. Here you can talk about broader aspirations in life e.g. do you want to ever have a relationship, go on holiday, have a job etc?

Contemplation: they will be very much in two minds. One day they will say they are frustrated, the next they may say nothing is wrong. At this stage the best thing you can do is reflect back what they are saying, "so on one hand you think this but on the other you think that?" If you start pointing out what is not helpful about the illness they will get defensive and more go back to pre-contemplation.

I don't think they're being honest about what they're eating, what can I do?

Primarily, it is their responsibility to eat what they should be and home leave is the best way for them to learn to eat responsibly. If you are concerned, asking them direct questions about what they have eaten is the best way to tackle this issue, if you feel comfortable to do so. Although, you may still not get the answer you were expecting and it is important to bear in mind that due to the nature of the illness they may be deceptive. It is also important that you feed this information back to the team.

What should I do if they won't eat what they should be eating?

Whilst on home leave they may have lower calorie alternatives to what they should be having according to their meal plans for example, skimmed milk instead of semi-skimmed, sweetener instead of sugar etc. We encourage them to stick to agreed meal plans and portion sizes as much as possible and would expect them to follow the same rules at home as they do on the ward. They may experience difficulty with this the first few times they go on home leave but as they near discharge they should be achieving this more consistently. If you are supporting with leave you can gently challenge them on these points however, it may be more beneficial to look at what they are achieving rather than what they're not managing well. Ultimately the responsibility of complying with meal plans etc lies with them.

I think they are over exercising or doing too much physical activity, what can I do?

Be aware of the rest periods they are expected to follow on the ward and their current activity allowance. You may want to remind them that they should be sticking to this. You may also want to plan activities with them that mean they will be doing something to distract them whilst on rest, for example, doing a crossword, watching a film etc.

I think they are vomiting, what can I do?

Don't panic! If there is direct evidence that they have vomited it is best dealt with in a direct, non-emotional way, for example, tell them you have seen vomit in the toilet and ask them to clean it up (this is how we would deal with incidents of vomiting on the ward in the first instance).

Later, you can offer them emotional support and reassurance. If there isn't direct evidence but you have a strong suspicion it is better to ask them directly if they have been vomiting.
Again, feed this back to the team.

I want to comment on how well they look/are doing but am worried it will upset them.

This is a difficult issue for both sides to deal with as relatives and carers naturally want to comment on physical wellbeing but someone with an eating disorder will interpret this as failure. If you want to stick on safe ground, it is okay to give praise and compliments but try to avoid commenting on their physical appearance. For example you may want to tell them their hair looks nice or that they are wearing a nice outfit. As treatment progresses we would encourage people to accept physical changes, take compliments on board, understand why these comments are being made and accept they have worked hard to stabilise their physical wellbeing.

Day patient treatment

We provide a day treatment programme for individuals who are low in body weight and who need more intensive support with tackling their eating disorder than outpatient care alone. We also offer day treatment where patients receive specialist nutritional treatment, individual and group therapy sessions, supported meal groups and weight monitoring as part of their care.

The Group Programme

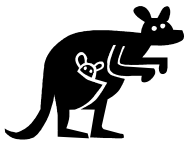
The Group Programme consists of specialised therapy groups for both inpatients and day patients if you would like to know more about these groups, the patient information booklets gives a brief description of each.

St Bernard Dog

A St Bernard dog is made of 3 C's: Calm, Compassionate, and Consistent. They are dedicated to the welfare and safety of those who are helplessly lost. They provide companionship, warmth and nurture. They are unfailing, organized, reliable and dependable in all circumstances, remaining collected even when the situation is dangerous. They do not panic or shout—which may cause an avalanche.

Second set is in relation to how you give direction to your loved one.

Kangaroo



A kangaroo wants to put the cared for person in their 'pouch', to keep them safe. They will do everything possible to support and protect, taking over all sorts of aspects of life in an attempt to help. They will wear kid gloves to try to avoid causing any possible upset or stress, accommodating all demands, whether they are rational or driven by the illness. They will offer to do things for the cared for, when really they could have done themselves e.g. I'll phone the GP for you, etc.

Rhino

A Rhino will attempt to persuade and convince someone to change by charging at disordered behaviours and beliefs and trying to smash them with logic and common sense. They are exhausted and frustrated by not being able to make things change – when they think there are simple solutions, e.g. attend appointments, see the therapist, take medication, and get a job/vocation.

Dolphin

A dolphin will swim alongside, sometimes in front, sometimes behind. A dolphin encourages, giving support when necessary but withdrawing to allow positive risks-taking. A dolphin knows when to do something for someone, with someone and when to let them do it on their own.

Helpful Resources Specifically For Families:

Skills-Based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method. J. Treasure (2007).

The Metaphors of Caring

People supporting someone with an eating disorder can get drawn into certain responses. Janet Treasure is a consultant Psychiatrist who works with eating disorders at The Maudsley in London. She has come up with these responses and talks more about them in her book.

First set is in relation to how we express our emotion.

Jellyfish

The Jellyfish can get engulfed in intense and transparent emotional reactions. Their sensitive and often tearful response may also be due to exhaustion and despair. This tends to come from self blame – they may believe they have failed as a parent, partner etc, or maybe they are perfectionists in your skills and expectations, and hold themselves responsible for the life and happiness of another.

Ostrich

An ostrich finds it difficult to cope with the distress and upset of challenging and confronting mental health behaviours. They will try to avoid thinking or talking about the problem at all, with their head firmly in the sand! Whilst trying to ignore the situation the ostrich may or may not be aware of the consequences for the family. They may avoid the home situation, by working or being busy rather than confronting difficult symptoms or behaviours.

Care programme approach (CPA)

Formal reviews of treatment occur approximately every five to six weeks during admission. These reviews are called CPA's and include the patient, their individual therapist, their primary nurse and other key people involved in their care. Carers and members of the home team are also invited to attend these meetings. Family members can attend as long as the patient agrees to this. Even if they do not agree to your attendance, you can still contribute any views you have. At these reviews, patients will have the opportunity to give and receive feedback from the team about the changes they have made and continue to keep making. These reviews monitor and detail the progress of each patient, focusing on how they can next move forward towards recovery. CPA's are also forums to identify personal aims, aspirations and goals they expect or want from treatment. The Treatment plan is discussed and towards the end of your stay a post-discharge plan will be agreed.

Outpatient treatment

Your friend or relative may also attend the service on an outpatient basis. This involves meeting weekly or less frequently with their individual therapist to discuss problems and issues that are important to them.

Family meetings

Family meetings are offered to inpatient and day patients, the family therapist along with a member of your nursing team (or sometimes along with the therapist who has met with the patient on a one-to-one basis) meets with the patient and members of their family. Friends may also have a useful contribution to make. Family members can often make a significant contribution to constructing a picture of how the illness began and what maintains it. Family meetings are about supporting both sufferers and those who they are in contact with and demonstrating their role in aiding and assisting prolonged recovery.

Family Therapy

Family Therapy is available to all families of patients receiving treatment at Cotswold House. It is also available for individuals, couples and other people who may be involved with a patients care. Family therapy is important in the recovery of eating disorders as it is a condition that affects family life and relationships. The aim of family therapy is to help families find constructive ways of helping each other that may not have previously existed. The purpose is to identify problems which may arise and support change to promote progress towards recovery. Family therapy is not about 'treating' or blaming the family/relations of those with an eating disorder; but to hear from family members about what the difficulties are from each person's point of view. It is also an opportunity to hear about how the illness has affected family members and to think together about what is the best way forward both for the person with the eating disorder and for family Members. As we are part of a teaching hospital, patients and family members may be asked if they are willing for other staff members to join a session or to observe a family interview.

Treatment and recovery

Although it may be a relief when someone starts treatment, they are unlikely to recover within a few weeks. It can take months or years to recover from an eating disorder. It will be easier on you and your relative or friend if your expectations are realistic. If your relative or friend is on a weight-gain programme, they will be expected to gain weight regularly. Weight gain is often frightening and patients often believe that weight gain will become out of control. Initially weight gain can be more rapid and unpredictable before it starts to slow down and level off. It is important to know that a sufferer is likely to be extremely sensitive to other people's perception of them. A positive remark such as 'it's nice to see you eating again' or 'you look healthier/ well' may be interpreted as 'I've failed', 'I am greedy', or 'I look fat'. Helping with these thoughts and perceptions is all part of treatment and working on them will hopefully help maintain progress in the longer term. You may feel optimistic that your relative or friend is better if they are looking healthier, have started a relationship or started working. However, they may not feel better emotionally or physically.

Returning to work or study is a big achievement, and people's ability to cope with it will vary. Try to stay supportive and encourage them to talk about their feelings. Recovery is gradual and unpredictable. Some people will learn to manage their disorder but never completely overcome it. Others take longer to overcome the disorder and can find themselves vulnerable to relapse when life becomes more stressful. Others get over their eating disorder relatively quickly and it does not affect their life greatly again.

How can you help someone with an eating disorder?

It is useful to think of people with eating disorders as being emotionally and physically dependent on behaviours like bingeing, starving, obsessively exercising or using laxatives. It will be difficult for someone to give up a way of life that has helped them to cope. It will be frightening and they are likely to experience a number of setbacks. So you may have to be prepared to be supportive over a very long period of time. The causes of eating disorders are numerous and are an interaction between a range of factors. Some things will predispose an individual to be vulnerable to developing an eating disorder and others will act as triggers for the illness. The physical and psychological effects of eating disorders also cause changes in mood and concentration, and therefore help to maintain the problem. Even the best family, friend or therapist cannot make someone change if they are not ready to change for themselves. It is possible to help someone to find positive reasons for why they may want to give up these behaviours for themselves and to support them to do so. Motivation for change has to come from them. If they start treatment to keep other people happy, the treatment is unlikely to succeed in the long term. There is a right time to change and this cannot be rushed, painful as it is to watch someone you care about behave in this way. We like this statement from B-eat in regard to supporting people with eating disorders "You alone can do it but you can't do it alone". This strikes the balance between the need for change has to come from the person with the eating disorder but acknowledging they will need support with this journey. People who do the best have supportive family and friends, a good care team and take responsibility for their treatment.