

**New Maudsley Skills Workshops for Carers
Collaboration and Confidentiality
Not mutually exclusive after all**

These workshop capsules have been created from scenarios considered in previous workshops and are designed to help carers to review and reflect on specific areas that can prove extremely difficult. All names have been changed in the scenarios.

Relevant New Maudsley Training Manual Exercises 6.7, 6.8, 6.9

[New Maudsley Carers - newmaudsleycarers-kent \(newmaudsleycarers-kent.co.uk\)](http://newmaudsleycarers-kent(newmaudsleycarers-kent.co.uk))

Research has shown that a collaborative care approach can significantly improve the recovery journey and result in better outcomes. In this capsule we review and reflect on the challenges that carers often face when trying to work collaboratively with their loved one's care team. Carers often feel excluded, patronised, judged, blamed, criticised, ignored and belittled and not surprisingly have become very angry and frustrated. At the same time members of the care team can feel criticised, unappreciated, frustrated at the lack of funding and exhausted by the constant battle of trying to provide the best possible care with inadequate resources and little training. No wonder there can be so much tension at this difficult time. At the end of the day both parties have the same goals:

- **to keep the patient safe**
- **to help the patient on their road to recovery;**
- **to work in harmony using a collaborative approach;**
- **to respect everyone's rights to confidentiality;**
- **to ensure carers and medical professionals are role modelling the importance of self-care and non-critical, compassionate communication to the patient.**

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Introduction

When my 12 year old son was ill and admitted as an inpatient to a general adolescent unit we naturally wanted to be involved at every stage. It is a very strange feeling to have to leave your son with a bunch of strangers, however competent and experienced they might be. To start with, I have to admit, I was a bit like a (raging) “bull in a china shop”. I wanted to know why, how, how long, when, and then why, why, and why again and again. It wasn’t that I didn’t trust the team but I was very scared and asking questions helped me to allay some of my fears. Of course, they didn’t have all the answers. Particularly to the “how long will you be keeping him here?” and to start with they must have thought I was an overbearing and interfering parent that needed to be kept at arm’s length. Indeed, in those early days we often had very different views on Joe’s progress and at times the relationship was very strained, but we were lucky in that, as a family, we were never totally excluded. Fifteen years on and I have provided support to hundreds of families whether by phone, e-mail, Zoom, or face to face at our carer support group, at the carer skills workshops and at conferences. Many carers find that talking to their doctor and even psychologists and psychiatrists is often not straightforward and many health professionals who struggle with these most complex of disorders hide behind a smokescreen of “confidentiality” adding to a parent or carer’s confusion and concern. Carers have valuable information based on their relationship with the patient which can provide details of behaviour which are never revealed by the patient to the treating team.

Open communication and talking therapy is the key to recovery from eating disorders and except for those few cases where some sort of abuse is at the heart of the problem, parents or other close family members should be informed and involved with the whole treatment process.

Nevertheless, it is important to distinguish between the confidentiality of the consulting room and straightforward information about the progress of treatment. The relationship between patient and therapist can be slow to develop and difficult to unravel so it is entirely appropriate for the conversations during therapy sessions to be confidential in every sense of the word. However, being prepared to discuss how the carer can help, and to address important carer concerns should be the sort of dialogue that should be routinely included in the care pathway.

Sadly, many carers still find themselves having to fight to be included in the therapeutic process instead of being there by invitation from the professionals. This often leads to even greater stress and disharmony in the family. This booklet contains practical tips on how best to approach the medical professionals initially, how to stay involved as treatment progresses, and how to keep communication lines as open as possible at all times.

Many people find that pressurised and confused health professionals can use the age of the patient (this might be 16, 17 or 18 years old depending on the service provider) to choose not to communicate with parents and carers. This is not rational or therapeutic as patients and carers are left adrift during home leave and on discharge. The UK Government NICE guidelines specifically recommend that all family members should be included in the treatment of children and adolescents with eating disorders. The Royal College of Psychiatrists and the Carers Trust also recommend carers of adult sufferers should be included and provide guidelines for best practice. We will review key elements of these recommendations in this document and some of the key points are listed in Appendix 1.

What information can be shared without breaching confidentiality and why?

Much has been written about the valuable role that carers play in the treatment process for their loved ones struggling with mental health issues. There are two basic tenets:

- a) Carers are entitled to be treated with respect and have their role valued and their efforts acknowledged by the care team.
- b) Carers should always be listened to and should never be excluded from a care plan particularly when the care team are assessing risk.

Beyond these basic tenets the wishes of the patient of course needs to be taken fully in to account and confidentiality wishes of all parties should be noted carefully and reviewed regularly.

Let's start on a positive note and adopt a "can do" approach, and consider what information can always be shared without breaching confidentiality. Even when the patient withholds consent the carers should be given sufficient information to enable them to provide effective care on an ongoing basis. This would include:

1. Information on who in the team is in charge of the overall care plan.
2. Who is providing day to day care, including meal support.
3. What different professionals do and how often they provide either 1:1 sessions, group sessions or other types of support and therapy.
4. How often risk is assessed and what the parameters are.
5. How often the review meetings are held.
6. Receive invitations to Care Planning meetings.
7. Receive support in order to develop compassionate communication skills with their loved one.
8. Information about the diagnosis, and prognosis.

The NHS website has information around carers engagement and it is worth looking up any guidance for your area. For example, the South London and Maudsley website [Information for carers \(slam.nhs.uk\)](https://www.slam.nhs.uk) states:

If you provide care or support to a friend or family member, our [Carers Charter](#) means:

- your essential role and expertise is recognised, respected and encouraged
- you are given the information and advice that you need to help you provide care
- where possible, you are involved in the planning and agreement of the care plan for the person you support
- your needs are recognised and responded to through a Carers Engagement and Support Plan
- you receive appropriate help and support when you need it
- you are actively involved in the planning, development and evaluation of services
- you know what you are entitled to expect from services

For more information [see the full version of our charter](#), or download [our Carers Charter poster](#).

So, what can be considered to be positive and useful information sharing:

- 1) At the beginning of the treatment process carers are likely to have key information relevant to the safe and effective care planning for the patient. They may know more about the history of the illness than anyone else and this information can be invaluable to the care team. They will also be able to provide valuable information about the well person before the illness took hold. With my son the care team observed that he had

quite severe obsessive compulsive tendencies and they wanted to prescribe an antidepressant to help with this. I could explain that these tendencies had appeared with the starvation and were not part of the “well” child. We agreed to hold off the medication for the time being and reconsider once he had gained weight. Sure enough, as he gained weight the OCD tendencies reduced and eventually disappeared without the need for medication.

- 2) The care team should ascertain what information carers already know, as any such information should not be treated as confidential. If you can provide a concise written summary of what you know already this can be extremely helpful. It is good practice for each care team to have a separate file for carers and your list could be a useful prompt for a file to be set up at the earliest stage. In addition, carers have the same rights to confidentiality as the patient and so information you provide should not be repeated to the patient unless you give permission.
- 3) One of the things carers struggle with most is what to do in an emergency and very often the guidance is “if you are worried go to A&E”. Try to establish at an early stage if the service has a 24 hour helpline, who your main point of contact is, and what to do if it is an emergency that would be better dealt with by a specialist mental health team who knows your loved one, rather than A&E who will not be equipped with your loved one’s medical history or care plan. Carers always should be provided with advice on what to do in a crisis:
 - Advice on managing the behaviour in the home and wider community, particularly in a crisis situation
 - Contact details of the care co-ordinator and assurance that when you make contact you will get a response

You might find the separate capsule on **Going to A&E** useful.

- 4) Throughout the treatment process carers are likely to have valuable information about how things are progressing in the outside world. Most patients will not be in patients and might only be interacting with the care team for an hour or so each week, or in some cases even less than that. When patients are seeing the treatment team, they may well give a rose-tinted version of how things are going, and/or it may be that the persuasive eating disorder voice is having the upper hand.

Scenario – Alice is 18 and has recently been transferred to adult services. She sees her therapist once a week and seems to get on well with him. Her parents are extremely worried as they can see that Alice’s weight has started to drop again and she is displaying many of her original eating disorder habits. She has become very moody and defiant and tells her therapist she doesn’t want her parents involved. Her parents call the service and they leave several messages but get no

response from the therapist. They are told by the receptionist that if they are worried, they should go to A&E. In the end they write a letter to the service manager setting out their concerns and stating that all they are trying to do is provide useful information. They do not in any way want to breach Alice's rights to confidentiality. At the very least they know that they have passed this information through but they remain frustrated at the lack of communication. A month later Alice goes out with her friends and gets so drunk her parents have to rescue her. This serves as a wake-up call and Alice agrees to be more open both with them and the therapist about how things are going. She recognises that it might be useful for the therapist to have a dialogue with Mum and Dad as long as the details of her therapy sessions are not discussed.

Note : In this scenario Alice's parents log their concerns in writing. This is very important as it not only shows the care team that you have some serious reservations about the care being offered, it will also be kept on file and can be referred back to if things don't improve.

- 5) Expanding on the recognition of the valuable role carers play, carers may be the only parties to offer continuity of care through the illness especially as friends and work colleagues can fall by the wayside if the illness has been going on for some time. Carers need to be included as part of the treatment process to ensure they can fulfil this ongoing role to the best of their ability
- 6) In addition, carers may be the only avenue of support when the patient is discharged from treatment. This can be a very vulnerable time when the patient might be physically in much better shape, but emotionally still very fragile. Informed, included and educated carers will be in a much better position to support their loved one through this difficult phase of recovery.

Who is a carer?

The Triangle of Care (see appendix) describes a carer thus:

“If someone is involved with and gives significant support to another person irrespective of whether they live with that person or not, they should be considered to be a carer and be actively engaged by the care team. This applies even if the person being cared for is unable, or even unwilling to acknowledge the carer's involvement.”

So, a carer can be a mix of relatives including parents, children, siblings, partners or friends. Their common ground is they want to help the person they care for to be safe and to recover. One or two carers are likely to have primary responsibility for caring for an

individual and it is important that members of the mental health team record who these key people are.

Carers have many rights to both information and support, and service providers should promote awareness amongst carers about their rights. This can include carer assessments and financial support as well as a right to be an important part of the treatment process.

What might be available for carers?

Always ask if the service has a leaflet or information pack for carers. So many times, I have been told that carers have been sent away empty handed when I know that there is a carer pack, or that the service has information about local support groups and other help available for carers.

For example, the South London and Maudsley NHS Trust has a [Handbook for Families and Carers \(slam.nhs.uk\)](http://slam.nhs.uk)

Hopefully any carer packs should have details of further help through Beat, FEAST,, local self-help groups and other relevant charities as well as a useful list of resources.

Things can change very rapidly within services, but the key message here is that it is worth asking what is currently available in your area both within the service and in the local community.

Recognising why carers can feel so aggrieved

Carers are often at their wits end by the time their loved one actually gets to see a mental health professional. They may have watched helplessly as their loved one has deteriorated and become more and more entrenched in their eating disorder behaviours. They are likely to have done much research and discovered that early intervention is crucial, but then had to face up to the stark reality that the NHS is so under resourced that crisis care is all that can be offered. All they want to do is help their loved one, but the system seems to them to be feeding the eating disorder, not treating it. This process can be lengthy and go on for many months.

Even the most robust and resilient carers might be feeling some or all of these, and this is by no means an exhaustive list:

FEAR – that my loved one might die, and that by challenging eating disorder behaviours I might be making things even worse. I don't know if my loved one will ever get better.

GUILT – was it something I did to cause the eating disorder in the first place? Is it something I am doing now that is making things worse?

SELF ESTEEM – I don't believe I can stand up to this illness. I am not equipped with the right skills. We are not worthy of help.

SHAME – I must keep others away from the home because of the shame associated with the eating disorder. I am ashamed that I cannot feed my loved one.

EXHAUSTION – this has been going on for so long that I can never see a way out and I am too exhausted to challenge these behaviours.

So, when their loved one gets a diagnosis and then an appointment there can be a great feeling of relief and joy. The carer will be hoping this will provide all the answers and perhaps be feeling for the first time that their loved one might possibly get better.

“I went to that first appointment full of hope and joy. I came away with more questions than answers and I felt that the consultant was somehow blaming me for my son's illness”

“The consultant told me to go away and feed my child and bring her back when she weighs 8 stone. Then they could think about therapy.” “IF I COULD FEED MY CHILD I WOULDN'T BE HERE!!!!”

“My son doesn't want us involved in his treatment and so we were told this and left with no information whatsoever”

These are a few examples, and I don't need to labour the point. One of the problems is that the carers are feeling super sensitive. They have gone in expecting a great deal and once they have realised there is no magic wand the meeting has deteriorated fast. The Triangle of Care and leaflets such as those provided by SLAM can help carers to really prepare for these initial meetings to make sure they maximise the chances of starting off on a positive footing. See appendix for details. I encourage carers to download these leaflets and highlight anything that seems relevant.

Recognising why care teams can feel so defensive and criticised

One of the most powerful exercises we do in the carer skills workshops is to imagine we are in the professionals' shoes.

Scenario:

It is Sunday morning and James, who is 15 years old, has just been admitted to an adolescent in patient unit. He has lost 25% of his body weight in three months and is very ill. His parents had to rush him to A&E the previous night because he had collapsed after doing an hour of intensive exercise. They have been up all night. Mary is really tearful. Robin is feeling angry and frustrated that they haven't been able to get help sooner.

Mary and Robin have a short meeting with the keyworker Rosie, who has been supervising James' admission. Robin demands to know why they are not having a meeting with the

consultant psychiatrist and states that he will be making a formal complaint. It is unbelievable that this can happen in this day and age. Mary sits and sobs. James states that he is fed up with his Dad shouting and his Mum crying and can they just leave now. Rosie has had a really stressful few days and this is the third time she has been shouted at by a parent who is threatening a formal complaint.

So, imagine how Rosie might be feeling:

EXHAUSTION – this happens so often these days and I don't know what the right answer is. Whatever I say right now isn't really going to help. This is so draining and exhausting.

FEAR – if parents keep complaining I might lose my job. The consultant psychiatrist is going to think I am totally useless.

FRUSTRATION – these poor families are right to complain. Why don't we have more resources? The government keeps promising so much yet delivering so little.

SELF ESTEEM – This service we offer is useless. I am useless.

SHAME – I am ashamed that the service we offer is inadequate.

So, Rosie completely understands why Mary & Robin are so upset, and to a certain extent she feels the same way. All she can do in this moment is to try and calm the waters and encourage Mary and Robin to leave James in their care and try to arrange for a proper meeting with the consultant as soon as possible. Staff working in these settings often get stressed and burnt out and there can be a high turnover of staff. Carers who can prepare well for these meetings can help to reduce some of this distress and are more likely to be able to work collaboratively with the team going forward. The aim of this exercise is to build empathy and introduce the concept that careful planning for meetings is really worthwhile.

If you fail to plan, you plan to fail! In this scenario Mary and Robin didn't have time to properly plan for the meeting. However, they could go home, review and reflect and take time to really prepare for the next one to maximise the chances of a better outcome. Writing a list and regularly reviewing it can be really helpful.

What about the patient?

In the scenario just described James has clearly stated that he would like his mum & dad to leave. This is really hard for them to hear, but might be sensible for the moment.

When the patient is first diagnosed he/ she may well be medically at risk and emotionally numb. Our son Joe certainly fitted this category. He sat in the room in a complete trance, gazing at the floor. In contrast I was like a ball of inflamed energy. I wanted a thousand answers to a thousand questions. Our keyworker was very kind and calm. She explained that Joe was likely feeling absolutely exhausted and that this was not a good time to be talking

detail. There would be an opportunity for this very soon, just not right now. She clearly stated that she would call us in the morning to let us know how Joe had settled in and then we could plan further meetings at the appropriate time. It was incredibly difficult to leave our son in this strange place with strange people. She was absolutely right though as we would have gone round and round in circles, I would have become more frustrated and Joe would have become more distressed.

So, what if the patient is asked at this point if he wants his parents or carers to be involved in his treatment programme? I imagine at this point James from our previous scenario might have said no. Joe might also have said no. What about a 24 year old girl? Also, likely to say no, because at this point the eating disorder voice may well have the upper hand. "Don't let your parents be involved. They just want to make you FAT"

This may well not be the time to insist on your involvement. There is another good reason why patience might be a virtue here. The team will be wanting to assess the patient and get her/him to engage as quickly as possible. If the care team are insisting that the carers are closely involved right from the outset then this could potentially damage that engagement process. By being patient, you are showing that you believe and trust that the care team are professional in their approach and will do their best to engage your loved one. Of course, there will be things you can know at this stage, and always ask if there is an information pack for carers. Remember a little bit of patience and trust in the care team can go a very long way at this point.

What is confidentiality? Why and how can it interfere with collaborative care?

Put a group of carers in a room and the subject of confidentiality is likely to come up very quickly. Carers feel disempowered and excluded which makes them incredibly frustrated and angry.

What do we mean by confidentiality?

Confidentiality is the right of an individual to have personal, identifiable medical information kept private.

Most carers are happy to respect this principle, but feel aggrieved when the professionals haven't even asked their loved one what they can disclose, and the professionals will not listen to the information that carers feel is important to bring to the table to ensure that an appropriate, safe, actionable care program can be put in place.

I teach emotional wellbeing and mental health in schools and the subject of confidentiality often comes up in sessions with staff. Staff know that they cannot promise confidentiality to students, and unless there is a child protection issue, parents will be involved if a student discloses that they are struggling with an emotional wellbeing issue. If handled wrongly then

the student may well withdraw and choose not to disclose whatever problems they are dealing with. Students may genuinely believe that the staff member will stand up in the staff room, or at assembly, and blurt out the student's inner most secrets. However, if the staff member adopts a person-centred approach which enables the student to have some control over the process, the student is much more likely to be comfortable with information being shared with appropriate others in the collaborative care network. So, the teacher might say:

"James there are certain people that need to be involved. These include your parents, form tutor, year head etc etc. However, we can discuss WHAT they need to know; WHEN we will tell them and, HOW we will tell them"

James will then understand that some of his teachers might need to know that he has an issue that might mean he is late in to class, he might need to leave early, he might need to take a break midway through a lesson, he might need a homework extension, he might need a reduced timetable. Those teachers don't need to know any more than that. Equally James's parents will need to know certain details but they don't need to know the complete minutiae of the conversation he has just had, or he might have in the future eg with the school counsellor. James is then likely to feel pleased that his parents will be able to support him, and equally pleased that he is allowed to have private conversations with the school counsellor. It is a balance.

The issues of confidentiality within the mental health setting can be difficult and complex to resolve. Examples of difficulties faced by professionals are:

Ethical and Legal Obligations – professionals owe a duty of confidentiality both to the patient and to their carers. A breach can lead to the professional facing disciplinary measures and legal proceedings including being sued or dismissed.

Consent – the patient must give consent before information can be shared with carers. This becomes complex when we start considering if the patient is capable of giving "informed consent". Many carers will argue strongly that their loved one is so malnourished that they do not have the capacity to give "informed consent". The professionals might see it differently.

Carers can also face problems with information sharing. They might notice that their loved one's physical condition is deteriorating fast but their child might not realise how unwell she /he is and might not want professionals to be contacted. If they contact services their loved one might then accuse them of breaching her/ his trust and confidentiality. This is a judgement call and difficult to handle for all. Carers can base their judgement on their knowledge and intuition and explain their reasoning to the mental health team and later to their loved one. The safety of the patient, psychologically and physically is the most important issue and discussions and decisions must include all those involved in providing care, in a transparent fashion.

Most eating disorder teams recognise that it is in the best interests of the patient for carers to be involved in the treatment process. They may also be regularly faced with young adult patients who are adamant they don't want their parents or carers involved, especially early on in treatment. One thing that can be reassuring is if the carers can trust that the care team will keep their loved one safe in these early stages. Remember that if life is in danger then the general principles of confidentiality no longer apply and many treatment centres will reassure parents and carers that they will be informed immediately if their loved one becomes very ill whilst in their care.

Things the care team might say and what carers might hear.

Because of the high levels of emotion in those early stages of the treatment programme it is easy for carers to misinterpret some of the care team's messages.

Scenario

Jacob is 24 years old and has had anorexia on and off since he was 15. He has been living independently in London for several years and coping well enough, although his Mum is constantly calling him and worries about his health. Jacob has had a relapse and Mum and Dad have had a very frightening experience, rushing to A&E and not knowing if he would make it through the night. It is not helpful that Mum has just read a book by a Mum whose son lost his life to anorexia whilst living in university halls in America. Jacob has now been admitted to an in-patient unit and Mum and Dad are meeting with the care team for the first time. These are some things the care team might say, and how Mum and Dad might hear them in the first instance.

"Jacob wants to be treated as an adult and take responsibility for his own recovery"

"It is appropriate for Jacob to want to be treated as an adult. He is 24 and has been living independently for several years"

"It is a really positive sign that Jacob wants to take responsibility for his own recovery"

Easy for an outside observer to see these are all good points, but equally easy for Mum & Dad to interpret these comments negatively and assume that they will not be invited to be involved at all. They might hear the message to be - "you need to back off and leave your son to look after himself."

The care team might also say:

"We have a great deal of experience and you need to trust us"

"We need to respect his wishes and he has a right to confidentiality"

"We need to let Jacob settle in and we need to establish a good rapport with him. This period of early engagement is very important and Jacob needs to feel he can trust us."

These are all valid points, but ones which carers might find very difficult to hear in the first instance. Recovery is a lengthy and complicated journey and there will be plenty of time to establish a good rapport with the care team in due course. Rather than taking offence at these early comments, carers can take this opportunity to step back, let their loved one settle in and engage with the care team, and then come back for a meeting that has been carefully planned for, at a later stage. This approach is more likely to increase the chances of carers being appropriately involved as the treatment progresses. It is also possible that once Jacob has settled in and engaged with the team, he will be much more comfortable about his parents being involved at some level.

Communicating with the care team when your loved one is an adult

Carers can use motivational interviewing techniques with their loved one's care team in the same way as they can use them with their loved one and other family members. Open questions followed up with plenty of affirmations for the good work they are doing and the skills they have, reflections to check you have understood correctly, and of course a summary to pull everything together, check you have understood what has been agreed and what are the next steps, and of course a time and date for the next meeting.

Working with the care team of a young adult

Scenario

Sarah is 21 and has a long history of anorexia, depression and personality disorder.

At the recommendation of her care team she lives independently and has recently had to move out of a halfway house because they needed the bed for a new patient.

Her parents have paid the deposit for her to move into a shared flat and she has agreed to apply for housing benefit, but finds this sort of thing very difficult. She is adamant that she doesn't want her flat mates to know about her issues and so does not want the crisis team turning up at the doorstep.

Her parents are also paying for her to attend a local college of further education where she has a personal tutor.

Sarah is not coping and has locked herself in the flat for the last three days.

Mum rings the care team helpline but is told they cannot talk to her because of confidentiality issues. Understandably Mum gets quite cross. The next day Mum decides to try again and with much persistence she finally manages to get a meeting with Sarah's care team.

Mum prepares carefully for the meeting to ensure that she doesn't forget anything in the heat of the moment. There are certain things she feels the care team need to know:

“Sarah hasn’t been out of the flat at all for the past week, and only twice in the past month”

“Sarah sees nobody”

“Sarah doesn’t look after her personal hygiene”

“Sarah is unable to apply for housing benefit so we have to support her financially”

“Sarah says things that indicate she is very depressed eg on her birthday she didn’t want to see anybody, simply stating – another year wasted”

“She has no joy”

Mum also thinks about the key questions she wants to ask:

“On a three to six month view how do you see her care plan progressing”

“Can you reassure us that you have sufficient face to face time with her to assess that she is not a danger to herself or anyone else”

“How do you measure her emotional/mental/physical state if you are not meeting with her face to face”

“How do you suggest we help her to start making progress”

“What could we do differently that might help the situation”

“What should we do if we are worried”

“We are constantly worried and this affects our emotional wellbeing”

Some other possible useful phrases Mum might use:

“Thank you so much for giving us the opportunity to come and talk to you today and we are so grateful for all the hard work you have done to help Sarah so far. We have been reading the Triangle of Care guide and the excellent SLAM carer leaflet. We feel we have some important information that we would like to share with you, and we want to make sure we are in the best possible position to carry on your good work once our daughter is discharged from your care”

“ Could you help us understand

“ So can I just check, what you are saying is

“ So you want us to

“Our daughter is very lucky to be under the care of such a wonderful and caring team.....

Summary

“Thank you so much for giving us this time today and we feel so much better knowing that we can all work together, whilst of course respecting our daughter’s right to confidentiality. It is very reassuring for us to be able to understand your approach and the care pathway you have in place. Also, thank you for explaining more about her

medications and the possible side effects. Can we pencil in our next meeting and could we have a contact number that we can call in case of an emergency, because it was so frightening for all of us when Sarah had an episode last week and we couldn't get through to anyone who knew her background."

When your loved one is a child or adolescent - Working with Child and Adolescent Mental Health Services (CAMHS)

You might imagine that it is much easier when working with a child as surely the care team will fully involve the carers. After all Family Based Therapy (FBT) is recommended as the optimum approach. In this approach which is well researched, parents are asked to take control of re-feeding, and should be given specialist assistance and support in how to do this. If the parents could easily feed the young person without support then by definition, they wouldn't be asking CAMHS for help.

Scenario

Ellie who is 17 has just had her first assessment with CAMHS. Both her parents attended the assessment and were very hopeful that this would be an important turning point for the family. Ellie had been referred to CAMHS by the GP six months earlier and had been warned that waiting times for assessment could be as much as 12 to 18 months. However, since the GP referral Ellie has continued to lose weight and so the GP has asked for an emergency assessment. During the assessment Mum becomes very tearful, she is exhausted with the daily battles, and extremely worried about Ellie's physical state. Dad tries to keep calm but the meeting does not provide them with the help and support they were hoping for.

Having assessed Ellie, the consultant sits down with all three and agrees that Ellie's weight loss is very concerning and that Ellie indeed has anorexia. She explains that this service follows the FBT approach in which it is crucial for the parents to take control of feeding. She gives the family a pre-printed meal plan and says Ellie should gain 2 lbs by the time of the next appointment in a weeks time. Mum and Dad don't argue with this but they feel like they are being reprimanded for not knowing how to feed their child.

Dad does ask about the possibility of any individual therapy for Ellie and/ or family therapy. The consultant explains that Ellie will be offered a course of CBT, but not until she has gained at least 8lbs. This is because Ellie might find it difficult to engage with any sort of cognitive approach at this low weight. She says family therapy might be available at a later stage, but can make no promises. All three leave the meeting feeling very subdued.

Mum & Dad decide to contact a local support group that a friend has recommended. At the group they discover:

- a) *There are several other families in very similar situations*
- b) *There are some carer skills workshops coming up, which they sign up for*

In the carers group session, some of the other carers suggest some things that they have found helpful:

- *Plan really carefully for any meetings with the care team*
- *Write down anything you are concerned about and/or questions you want to ask*
- *Make sure to praise the team for their efforts and be very grateful for the meeting*
- *Take a notebook to the meeting and write down anything that is agreed, and don't leave the meeting without establishing when the next appointment will be*
- *Ask for advice on what to do in an emergency and what are the warning signs of an emergency situation*
- *Ask about transition to adult services as you have read that it is good practice to have at least a 3 month handover period.*

A month passes and Mum comes to the first carer skills workshop. Things haven't really changed. Two of the appointments were cancelled at the last minute. Ellie is really struggling and has only gained 2 lbs, rather than the 8lbs CAMHS were expecting. Mum reports that the team at CAMHS seem unconcerned and just keep reiterating that Mum & Dad should take control of the eating. They have ducked the issue of transition to adult services on the basis that Ellie might be better by then. Once Mum has let off steam she is then very receptive to try anything she can to improve relations with the CAMHS team. She embraces the motivational language techniques to use both with the care team and her daughter, and learns about the importance and value of looking for green shoots.

Feeling energised by the workshops Mum has the strength to persevere and over the ensuing weeks, she continues using the skills she has learned. She tries to look for positives rather than being crippled by negative thoughts and feelings. After hitting rock bottom and a frightening emergency dash to A&E, things started to dramatically improve.

"After coming to the workshop, I really felt empowered to help my daughter. I was able to give a clear message to CAMHS about how things were going at home and what specific help I needed to be able to help my daughter to get to the weight target. Also, I knew how to approach CAMHS in a more positive way. Not wading in with welly boots and a critical voice, but acknowledging that we really needed their help and expertise and that we would like to work with them in a positive way. Since then CAMHS have been great, really supportive. "

Empowering carers to work effectively alongside the GP

Most GPs have little or no training in eating disorders and can feel very frustrated when trying to help and support sufferers and their families. Add to the lack of training, they are hampered by the very short appointment times in which to make any sort of diagnosis, the patient is likely to deny there is a problem, and often they have very few options in terms of offering support. In most areas of the UK there are long waiting lists both for adult, and child and adolescent services, and early intervention services are few and far between. GPs may have no option but to “watch and wait” which can easily be interpreted by the family to mean “go away and get sicker, then we might be able to help you”. In this section we look at making the most of your GP.

Whether you choose to go via the NHS or privately for treatment for your loved one, the first port of call will be your GP. To maximise the likelihood of an early diagnosis being made, carers are well advised to go armed with enough facts about the deterioration in their loved one’s health so that the GP will take notice. A well prepared and informed carer can help the GP to arrive at a diagnosis more quickly and increase the likelihood of a referral to specialist services. There are three key things that your GP is likely to be interested in and which might help them to recognise your loved one might have an eating disorder:

- How much weight has your loved one lost and over what time period?
- How has your loved one’s behaviour changed and have they developed any rituals or unusual habits?
- What have you tried at home to reverse the weight loss and why do you think this hasn’t succeeded?

If this doesn’t work, perhaps you can be more specific the next time. Carers can draw the GP’s attention to the MARSIPAN checklist created by the Royal College of Psychiatrists in 2015, and the SCOFF questionnaire which was developed by the Leeds NHS Trust to aid early detection of eating disorders. Appendix 2 has links to these documents and you might wish to download them and highlight things that are relevant for your loved one.

The MARSIPAN summary checklist provides a list of significant risk factors which warrant urgent assessment including

- Recent loss of 1kg or more for two consecutive weeks
- Little or no nutrition for over 5 days
- Acute food refusal or less than 500kcal a day for over 2 days in under 18s.
- Pulse below 40
- Core temperature below 35 C

If you observe just one of these then you should alert your GP and ask for an urgent referral.

The SCOFF questionnaire is often used and if 2 of the questions are affirmative this signifies a likely case of an eating disorder

The SCOFF questions*

- Do you make yourself **S**ick because you feel uncomfortably full?
- Do you worry you have lost **C**ontrol over how much you eat?
- Have you recently lost more than **O**ne stone in a 3 month period?
- Do you believe yourself to be **F**at when others say you are too thin?
- Would you say that **F**ood dominates your life?

*One point for every “yes”; a score of ≥ 2 indicates a likely case of anorexia nervosa or bulimia

GPs should also carry out a range of physical checks on a regular basis of any patient who has been identified as being at risk of having an eating disorder.

MIND recently produced a leaflet entitled “Find the Words – Talking to your GP about mental health” and for more information about getting support from your GP practice visit www.mind.org.uk/findthewords The leaflet gives good advice on preparing for the appointment:

The main one for me is to write down everything you want to say and take your notes with you. It can be useful for the GP if you can leave a copy of your notes with them. Finally, if you find that your GP is not helpful and/or doesn’t understand eating disorders you have every right to ask to see a different GP or even to move to another practice. Some GPs have much more experience and empathy for families affected by eating disorders than others.

Conclusions

Empathy for the plight of your loved one’s care team can go a very long way. Carers can use the motivational skills of praise for the team’s superb efforts to help their son or daughter and of course their expertise, balanced with empathy for the lack of resources. A positive approach suggesting that you, as carers would very much like to help in any way you can (you have background info and knowledge of the history of the illness that your loved one may not have shared with the team), and that you also wish to be prepared in the most optimal way to carry on their good work at home is much more likely to yield positive results from the care team.

So, save your anger, frustration and temper tantrums for the mirror or the dog!

If none of this seems to be yielding positive results and you continue to be worried that your loved one is deteriorating, then it is always worth considering making a formal complaint and your local NHS website will have details of the complaints procedure. It is possible to complain in a caring thoughtful manner.

Finally, always be aware of medical risk. Sufferers can deteriorate very quickly and if you see any of the warning signs then step in and take control. Carers are often in a position to spot these warning signs before the medical team who might only see the patient for an hour or so a week. Make sure you have a plan and know what to do in an emergency situation.

Appendix Best Practice Guides

Best Practice - Triangle of Care

The Triangle of Care (<https://carers.org/resources/all-resources/53-the-triangle-of-care-carers-included-a-guide-to-best-practice-in-mental-health-care-in-england>) is a Carers Trust project based on a guide developed by carers. The project works with mental health providers across England to look at how they can implement the six key standards that will see carers included, informed and better supported when they are caring for someone with a serious mental health problem.

The Kent & Medway NHS Trust are committed to Triangle of Care and have now cemented that commitment by signing up to the audit process. Check your local NHS website to see if they have a similar commitment.

According to the Triangle of Care there are six key standards:

- 1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- 2) Staff are 'carer aware' and trained in carer engagement strategies.
- 3) Policy and practice protocols re: confidentiality and sharing information, are in place.
- 4) Defined post(s) responsible for carers are in place.
- 5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
- 6) A range of carer support services is available.

Where carers are excluded this should be challenged

Carers should feel listened to, really heard and consulted more closely

There should be adequate recognition of the carers' knowledge of the well person.

Best Practice South London and Maudsley NHS Trust

SLAM has a leaflet that can be downloaded from

<https://www.slam.nhs.uk/media/13524/carers-and-confidentiality.pdf>

It is designed to assist staff to work closer with carers within the boundaries of current legislation and to help carers understand their rights.

Appendix 2 – Guidance for Assessing Medical Risk

Carers can print off any of these and highlight things that might apply to indicate that your loved one should be referred for specialist treatment.

The Royal College of Psychiatrists Marsipan Checklist

The full Junior Marsipan report can be found at https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr168.pdf?sfvrsn=e38d0c3b_2 and the full checklist is on page 17

Note there is a separate MARSIPAN report for adults with eating disorders at https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr189.pdf?sfvrsn=6c2e7ada_2. It is well worth reading if you are caring for an adult sufferer

The Institute of Psychiatry Eating Disorders Section (Kings College and the Maudsley) has several useful guides:

The IOP Guide to Medical Risk

www.thenewmaudsleyapproach.co.uk/media/Medical_risk.pdf

The SCOFF Questionnaire

[British Medical Journal \(bmj.com\)](http://British Medical Journal (bmj.com))