

ED Transitions Module 5:

Parents and Carers



Learning Objectives for Module 5:

This module aims to help eating disorders professionals:

- Access the information and skills needed to work alongside young people with eating disorders and their carers to ensure that there is clear support in place for both parties.
- Recognise that there can be a high level of anxiety for all those who are involved with supporting an 'emerging adult' through treatment.
- Understand the complexities around confidentiality and consent to ensure that there is effective collaborative care for the young person.

Introduction

Navigating how best to support loved ones through their growing independence, alongside age-related transitions, can be difficult and anxiety inducing for carers. Changes in expectations of family involvement between services and changes in confidentiality policies can exacerbate this, leaving carers in the dark about care provision.

Young people **mature at different rates** and the optimum level of family involvement will depend on the **needs** of the individual:

Introduction

I felt quite debilitated by being unwell. I felt that I needed to have more care and nurturing, so having the family on board and having them able to understand what I needed with the help of the therapist was really important.

Young person

I think it was important for me to have some independence with taking ownership of my own (difficulties)

Young person

However, no matter what point a young person is at, family and carers have a right to be supportive and are invaluable sources of **support** and **information** about the young people we work with.

Introduction

Understanding the experiences of carers as they navigate these changes and the complexities around confidentiality and consent can ensure that there is **effective collaborative care** for the young person.

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.

Carer

Introduction



Jenny Langley, lived experience carer and author describes two basic tenets of eating disorder treatment:

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 young person** need to be taken fully into account. Confidentiality wishes of all parties should be noted carefully and reviewed regularly.

Parental and carer involvement in treatment

Level of appropriate parental involvement in treatment will vary according to the **individual circumstances, wishes, values** and **culture** of each family. Many young people and their carers will want to work together in the best interests of recovery.

Clinicians, family and the patient can be a strong force for change and it's important that issues around communication are addressed at the outset of treatment and adapted along the way (depending on the stage of recovery).

It can be especially helpful to agree early on in treatment with the young person, how they wish to have their family members involved, or not, in their treatment. The involvement of parents or any other family member in treatment is likely to be far more effective when it has been agreed and directed by the young person.

Under the NICE Guidelines; General Principles of Care in the treatment of Anorexia Nervosa, it is recommended that families are involved during the process of assessment and treatment (as appropriate).

Parental involvement in treatment

Furthermore, some treatment approaches necessitate parental or carer involvement. This is the case in Family Therapy for Anorexia Nervosa (FT-AN) and Family Therapy for Bulimia Nervosa (FT-BN).

When working with children and young people with the relevant diagnosis, therapeutic approaches that involved the family are considered the first line treatment, unless considered “unacceptable, contraindicated or ineffective”.

For some families, this will involve parents attending appointments with the young person.

For others this will mean accessing carers support groups and/or carers skills training only.

Parental involvement in treatment

Occasionally, parents may want the opportunity to speak with the young person's clinician/therapist separately. Therapists need to be transparent with the young person about this.

Parents are advised to let the young person know that they have requested this and, ideally, what they will be speaking about, where it is safe to do so.

In some instances, parents may speak to a different member of the team.

Some clinicians prefer to address this by suggesting that the young person is always present when members of their support network are conversing with them.

Parental involvement in treatment

It is also worth considering "one-way" forms of communication wherein carers can contact clinicians with information they feel is relevant (e.g. if the young person is engaged in high risk behaviours) without the expectation of reply.

Email may be an appropriate channel for this type of communication.

All of these specificities around communication with supporters and carers need to be carefully addressed and thought through.

Parent and carer involvement and confidentiality: the law

Capacity:

People aged 16 years-old and over are presumed in law to have **capacity to make decisions** about their treatment (under Section 8 of the Family Law Reform Act 1969). Parents cannot:

- *override consent or refusal to treatment in competent 16/17 year-olds*
- *consent on behalf of their competent 16/17 year-old*

However, in most instances, it is commonly regarded as good practice for parents or carers to be **included in health care planning** as they are often **best placed to support** the young person with their treatment.

Parent and carer involvement and confidentiality: the law

Parental rights:

Mothers have intrinsic legal authority or Parental Responsibility over their children up to the age of 18 years (s3(1) Children Act 1989). This is unless someone else is appointed as a Legal Guardian via a court.

Fathers who are married to the mother also automatically have Parental Responsibility. Alternatively, fathers who are named on the birth certificate will also have Parental Responsibility.

This means that where important decisions have to be taken, mothers and married fathers are legally allowed to have a say. The law in relation to second female or male parents is different.

Confidentiality & Information Sharing

I think this cliff edge of confidentiality is crazy and I think it should be a more fluid boundary somehow. There has to be some common sense.

The extent to which parents are involved and the amount of autonomy that people have and are allowed to take their own risks should be able to change in a fluid way depending on the personality and where the person is at, over a period of several years when people are turning from children to adults.

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Confidentiality & Information Sharing

The same duty of confidentiality applies to young people (and children) as it does to adults. However, young people are often happy for information to be shared and many will assume information will be shared, having been used to this.

Furthermore, most parents want to be able to support their child's treatment and welcome guidance from professionals.

Confidentiality & Information Sharing

It is good practice to ask the young person if and what information they agree can be shared, and with who. For example:

Some young people are happy for parents to know what the care plan is but they want to communicate this themselves and they do not want parents to know what is talked about in one-to-one sessions.

Others feel comfortable with parents knowing some content of one-to-one sessions, perhaps where it is considered conducive to their recovery or circumstances, and want this conversation to take place within an appointment.

Others are happy for parents and staff to talk directly, in which case it is advisable to agree with parents that they let the young person know what is being discussed and why.

Confidentiality & Information Sharing

The young person's wishes and consent, in relation to confidentiality, and their parents' wishes where applicable, should be **recorded** within their notes so that it can be easily seen by other professionals.

It can also be helpful to set an alert within the system notes, so that this decision is **reviewed regularly** as situations can change rapidly during treatment.

It is important to note that the same universal limits to confidentiality apply to under 18's as over 18.

That is, where the young person's safety or the safety of another person may be at risk, it may be necessary to break confidentiality.

Key points to remember:

- Issues around confidentiality can pose significant dilemmas for clinicians.
- The issue of confidentiality needs to be weighed up with a risk assessment, particularly if the family member shares something worrying e.g. increasing suicidal risk for the patient.
- Ensure your service has a leaflet on confidentiality

What do carers think about confidentiality?

Jenny Langley suggests that there are a number of ways carers can be involved in their loved one's treatment even when consent is not given.

These could include:

- Respecting consent whilst maintaining connections with parents and carers (e.g. implementing "one way" comms wherein parents can agree to send teams information they feel is relevant about their loved one whilst understanding they will not receive information back)
- Providing information on who in the team is in charge of the overall care plan.

- Explaining what different professionals do and how often they provide either 1:1 sessions, group sessions or other types of support and therapy.
- Outlining how often risk is assessed and what the parameters are.
- Outlining how often the review meetings are held.

What do carers think about confidentiality?

These could include (cont.)

- Inviting carers to Care Planning meetings.
- Having conversations with parents and young people to clarify circumstances where high risk situations may necessitate changes to how confidentiality preferences are observed.
- Informing carers about who is providing day to day care, including meal support.

- Providing practical support and information to help develop compassionate communication skills with their loved one.
- Providing information about the diagnosis, and prognosis.
- Having conversations with parents and carers about consent.
- Having conversations with young people about consent and the implications for their carers.

What do carers think about confidentiality?

Additionally, in cases where consent for information sharing is not given, it may be possible for parents to be assigned a clinician not involved in the care of the young person in question as a point of contact.

This clinician can give generic advice and listen to concerns from the parent or carer, whilst the young person remains reassured that confidentiality is being respected.

Inform carers if/when consent is withdrawn - otherwise they can be dangerously deceived that all is well because they believe services would have told them if there was deterioration/serious risk (as per an earlier agreement, for which consent has since been withdrawn)

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What do carers think about confidentiality?

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.

Carer

Planning for Crises

A key concern for carers is often knowing what to do in a crisis situation, which can seem especially daunting if they perceive communication with the care team is impacted by confidentiality.

It is crucial that carers are always given clear advice on what to do in an emergency:

Advice on managing the behaviour in the home and wider community, particularly in a crisis situation, and how to seek crisis support both in and out of usual working hours.

Contact details of the care co-ordinator and assurance that when you make contact you will get a response.

Planning for crises

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 an out of hours 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.

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Recognising why carers may feel unhappy or aggrieved

Carers are often put under immense pressure as a result of the illness experienced by their loved one. The transition period brings additional complexities and concerns for parents who may feel that any hard-won progress in terms of accessing CAEDS treatment may be at risk.

On top of this, changes in confidentiality may feel like another barrier being put up by the 'system', making helping their loved one even more difficult.

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.

ED Professional

Communication with carers

When talking to parents and carers, remember that it is an extremely anxiety provoking time for all involved. Carers and young people are navigating **changes in roles** within the family as the young person explores their increased independence.

Feeling cut off from information about their loved-ones care due to changes in confidentiality can leave parents feeling helpless.

Carers may also experience understandable frustration if they feel they are not heard when voicing concern. They may not be in a place to be able to communicate in a measured way and might need a lot of **support** and **reassurance**.

Communication with carers

Transitions between services also take place over the back drop of difficulties in **accessing care** within the NHS:

There were a lot of missed opportunities.

A bit of support/training for parents (and KNOWING consent had been withdrawn!) might have kept daughter out of hospital.

Carer

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.

ED Professional

Communication with carers - working with difficult emotions around transitions

Parents and carers are often invited to psychoeducation and **communication skills** workshops. Some of the principles that are taught within these sessions also apply to our approach and communication style towards the young person and their families.

Some key points to remember when communicating with patients and carers (**7 Cs**):

CALM

Ensure the setting is not stressful

CURIOUS

Explore the emotions/concerns that lie beneath the ED symptoms e.g fear

CLEVER

Name and identify the emotions that are below the surface

COUNSEL

Listen and check that you have understood rather than jumping in to give advice

COMPASSION

Provide warmth and security

COMPENSATE

Build a positive resource to counter threat bias

COLLABORATION

The importance of working with the YP at their pace

Communication with carers - working with difficult emotions around transitions

Within the treatment of eating disorders, **motivational interviewing** (MI) is a communication tool that is regularly used to 'enable the person to take up their own argument for change'. MI is useful for clinicians to use with patients and carers.

We encourage clinicians to use the 'OARS' to **enhance communication** and **improve listening**. The OARS model is explained on the next slide.

Communication with carers – working with difficult emotions around transitions (OARS model)

Ask **OPEN** QUESTIONS

Be genuinely curious
“...and what else?”

AFFIRMATION

Give positive feedback about their efforts, intentions, hopes (avoid judgment on achievements)

REFLECTION

Listening carefully, noticing their emotions. Check out what you think they have said

SUMMARIES

A special type of reflection that shows you have been listening and understand what has been said.

Jenny Langley has produced some excellent training videos on the 'OARS':

- For more explanation on Open Questions click [here](#)
- For more information on Affirmations click [here](#)
- For more information on Reflections click [here](#)

Communication with carers – working with difficult emotions around transitions

Another technique used to communicate with young people and carers is '**PACE**'. This is a tool derived from **attachment based parenting**.

PLAYFUL

Adopt a stance where you try to focus on your own emotional posture – being relaxed and giving a sense of enjoying being in the other person's presence. Try to cut any existing tension.

ACCEPTING

This is about giving the opportunity and space for the other person to share their emotions, wishes and feelings. It is about demonstrating that you are okay to hear whatever difficulties/experiences they are going through

CURIOUS

Demonstrate interest and ask questions to better understand, and to know more about what is going on for the other person. Try to do this in a manner without judgement.

EMPATHY

This is about acknowledging the emotion that is present, and sharing your understanding of that feeling. This demonstrate sthat the other person does not have to experience difficult feelings alone.

Resources

Helpful tools and resources for carers:

It is very important that carers are **offered information** and skills to enable them to communicate effectively with their loved one.

Here are some resources that are useful to offer to carers:

- [Beat](#)
- [Maudsley Carers](#)

Useful websites on emerging adulthood:

- [Drugs and Alcohol:](#)
- [MIND](#)

Additional resources for clinicians:

Click on the icon to access some additional resources for this module:

- Explaining rights and confidentiality leaflet
- Lived Experience Viewpoint on Carer Confidentiality
- Involving Carers in Treatment Resources



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