

Service Users & Carers and the Care Programme Approach

# Making the CPA work for you

It is **not** about how you fit into services
It **is** about how services fit with you

[See also DVD: 'MAKING THE CPA WORK FOR YOU'

Available from the Department of Health]

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# What is the Care Programme Approach (CPA)?

The CPA has been part of mental health services since April 1991; but unlike medication or counselling, it is not something you can take or something that is done to you. Being 'on' or 'off' CPA should not stop you receiving a particular service that you need. CPA is simply a term for describing the **process** of how mental health services assess your needs, plan ways to meet them and check that they are being met. You should always feel able to ask mental health workers to explain this process clearly to you.

As an approach, it is about making sure that your care and support are offered within a set of reasonable **principles**:

- > Assessing your needs with you, in relation to any given situation.
- > Developing a plan with you, in response to the needs identified and agreed.
- > Sharing responsibility with you (and others as needed, including family, carers and friends who provide unpaid support), to put the plan into action.
- > Reviewing the plan *with you* and others who provide support, periodically, to see that it is meeting your needs and to agree any changes.

It is also expected that all people providing services do so within a set of personal and/or professional values that:

- > Show respect for you as a person, including recognition of your personal strengths and qualities.
- > Respect your dignity at all times.
- Offer you information about reasonable choices you can make regarding your care and support.

- > Demonstrate respect for equality of opportunities for all, regardless of ethnic origin, gender, sexual orientation, cultural or spiritual beliefs.
- > Help you feel as in control of the whole process as possible.
- > Respect the views of people who are important to you.

Even though the CPA is specifically applied to services in Mental Health NHS Trusts (e.g. the community teams and inpatient units), because these **principles** and **values** describe what good practice should look like, you should expect them to be a part of every contact you have with anyone providing a health or social care service for you. These **principles** and **values** apply to:

- > Any consultation you may have with mental health professionals.
- > Any regular contact with local voluntary agencies offering care or support.
- > Any programme helping you with education or return to meaningful activity.
- > As well as the different contacts you may be having with different teams and agencies over many years.

CPA is... a way of describing what you need in order to get all your needs met. You have a right to a reasonable amount of choice about when and how you wish to be treated, wherever possible. The CPA is an approach that should continue all the time.

# What is changing?

Since 1999 all Mental Health NHS Trusts across England have had to make arrangements to consider whether people in contact with them should be placed on Standard CPA or Enhanced CPA levels. Those on Standard CPA have usually only had contact with one or two mental health professionals in response to their needs; and those on Enhanced CPA have usually required a number of different people providing services from different teams and agencies.

- > The most significant change that you may notice is that the Standard CPA level will be removed.
- > The CPA has been reviewed to make it more flexible, so only those who need a range of services co-ordinating to meet their care plan will need a care co-ordinator to carry out this role.
- > The less noticeable change for you will be the messages to the organisations and services themselves. They will need to support their staff to deliver their services in line with the clearly defined **principles** and **values** that guide good practice.
- > There should be less attention to talking about different levels of CPA, and more time spent on providing the services and support to meet people's agreed needs.

#### Who will be 'on' CPA?

- > It is not something that you can either be 'on' or 'off'.
- Most people, previously receiving Enhanced CPA will still experience care co-ordination in the 'new CPA' because they have complicated needs.
- > Some people will still move into and out of this category as their needs change.
- > Everyone in contact with mental health services, and their family and carers, should expect to be treated in line with the **principles** and **values** outlined previously.

Providing a service in line with **principles** and **values** of good practice should be something that all staff providing services want to do. So, there should be less concern about providing different services depending on different levels of CPA.

All 'Points you might want to think about' in this booklet can be used by individuals, or in local group discussions.

#### POINT 1:

Were you on Standard or Enhanced CPA?
What do you feel was good or not so good about it?
Who can you discuss previous benefits or concerns about CPA with?

# Will changes to the CPA mean I get less of a service?

No, the CPA is not a system just for getting or not getting particular types of service, nor should it be a badge of entitlement to specific services.

- > This will require many of the people providing different types of service to change the way they think about the purpose of the CPA.
- > The CPA should simply describe what you should experience as good practice from anyone providing you with a service.
- > The CPA provides a guide to what you should expect, and indeed ask for, from health and social care professionals and workers in other agencies.

Many people have previously experienced confusion and frustration with the CPA. This is because different people, and services, have misused it as a way of gaining or denying access to other services or entitlements. As an 'Approach' it is more about the way things should be done with you, not so much about what you can or cannot get.

- > The changes are *not about* removing care from people in need.
- > Receiving social security benefits is independent of the CPA, nobody will lose benefits as a result of these changes.
- > They *are about* removing some of the existing complicated paperwork and administration that local services spend unnecessary time focused on.
- > Removing what used to be known as Standard CPA means that a good service responding to needs is something that applies to everyone.
- > The CPA sets out what you should expect in all contacts you have with people providing services.

A more complex group of people will still be identified because they have more complicated needs and services involved. This means a different level of response will naturally be required. But everyone in contact with services should expect as a right, and feel able to demand, a good service in response to their needs.

#### POINT 2:

Do you think the changes to the CPA are really about providing less of a service? What would need to happen locally to help change your mind? Who can you talk to about this?

# POINT 3:

Ask the people who are providing mental health services for you (or for the person you care for) what they think the CPA is about. Discuss with them any of the messages from this booklet you think are important to you.

# What about my choices?

Providing a good quality service in response to your particular needs, as a service user or as a carer, requires staff to gain your trust, as much as possible.

- > It needs to be about you... what you need and want just as much as about diagnosis, treatment and support.
- > The **values** of the CPA mention the importance of providing information to support you to make choices.
- > This booklet will set out ways in which you may be able to choose how you want your needs to be assessed, what plans you want to meet them, and how you want progress to be discussed.

There has to be degrees of flexibility on behalf of those providing services, in order that they can respond to you in the ways that may suit you best. However, there also has to be flexibility on your part in understanding that the services only have limited resources to meet great demands. The range of choices that they may wish to offer will not always be available.

#### POINT 4:

Feel able to express your choices to the people providing services for you. Feel able to ask for reasonable explanations if your preferences are not able to be met. Not being able to meet your specific preferences does not necessarily mean the service providers have failed you.

# Does the CPA apply to my General Practitioner (GP)?

The GP is the first point of contact for anyone trying to get help with their health. This is known as the Primary Care system. The GP would refer you on to specialist mental health services if they thought there was a specific need. These services are known as the Secondary Care system. Since 1991 the CPA has applied specifically to the secondary care system, so in this way the GP is not strictly governed by the CPA. However, because they are so important to your care they should always be contacted, included and informed about arrangements for your care and support through the process of the CPA.

GPs are rarely able to attend review meetings within the process of the CPA, unless the review can be particularly arranged not to clash with the other demands of running a busy surgery. If your choice is to have your GP present in discussions about your progress you should make this clear to the mental health staff working with you. Attempts can then be made to achieve this. Reviews within the CPA process can be held at the GP surgery, if this is your preferred choice and the GP practice is able to accommodate the request.

#### POINT 5:

Check the original principles and values stated for the CPA earlier. In what ways are these already happening each time you visit your GP?

# What Does Care Co-ordination Mean?

It is only natural that you will experience different types of needs at different times. It takes careful co-ordination in order to ensure they are met as promptly and efficiently as possible. *Care co-ordination* is about making sure the right services are responding to your needs in ways that have been agreed, usually with you and the people who are important to you.

#### POINT 6:

What is it about your needs, at this point in time, that means you require a number of different people or services to be working with you?

#### What will a care co-ordinator do?

If you have a *care co-ordinator* they should be able to explain to you how the different services are meeting your different needs. They will be in regular contact with each of the people providing services for you. They keep an eye on how the whole jig-saw is fitting together. They will be a point of contact for you, and your family/carers, should you need to make contact with them.

# When might I need a care co-ordinator?

When you are generally in contact with only one or two people (e.g. Psychiatrist or Psychologist for regular appointments, a Nurse for depot injections) they will be co-ordinating their own contacts with you. They should also be in contact with any others involved (as well as your GP). They may not officially be called a care co-ordinator, but they are doing this role at a very simple level.

Where your needs have become more numerous or complicated, a range of different services might be required in order to meet them properly. Co-ordinating these different services becomes a more complicated job in itself.

Where you are in contact with any community teams in the secondary mental health services, they will need to make a judgment as to whether a named person needs to take on the job of co-ordinating all these services together.

- > Care co-ordination is the way of trying to see that all the pieces of the jig-saw stay in place.
- > It is the means for keeping the services in check, not the means for keeping you in check!

#### POINT 7:

The worker you are seeing (whether they are a care co-ordinator or not) should explain about all the services you receive. You have a right to ask. You should keep their contact details in ways or places that will be easiest for you to remember.

#### Who can be a care co-ordinator?

Having the right person named as your care co-ordinator could well determine just how much you feel accepted and understood by services. It could also affect how able you feel to engage with them.

Most usually this will be a Nurse, Social Worker or Occupational Therapist in a community team you have contact with.

- > Ideally it should be the person who knows you best, and who you feel most comfortable to talk with.
- > An unqualified person within these teams, or in the voluntary sector, housing support, or independent sector services could be the best person to be a care co-ordinator for you. *But this will require local agreements* to be made between the different agencies providing the services you need.

If you need to go into hospital for any reason, or have contact with crisis services, the care co-ordinator should remain in contact with you. You may notice that staff in the other parts of the service may have more contact with you for short periods of time.

Whether *or not* you come within 'more complex care co-ordination' should not take away your right to expect and demand to be treated in accordance with the **principles** and **values** that are the CPA. Everyone who provides a service should be expected to deliver good practice.

# Who chooses the care co-ordinator?

- > You may have some choice in who is allocated, (services will usually try to ensure gender, culture and ethnicity specific requests are met, where possible).
- > But, the services also have to balance all of the work they expect their staff to do, so this may not always be the case.

# Can I be my own care co-ordinator?

You, or your carer (relative or close friend), are the people with the best knowledge of what is going on for you. However, you will be less likely to be in a position to know the range of services that are available, and how they are accessed. This would make the role more difficult for you to achieve yourself. If you do try to co-ordinate your own care, you are still likely to need the help of someone you trust working within the services.

#### **POINT 8:**

If you are being offered a choice of care co-ordinator who do you think would understand you and relate to you best?

If you do not have a specific care co-ordinator, who do you trust most to ask any questions about how services are being provided for you?

# What Assessments Might Happen as Part of the CPA?

# What is a comprehensive assessment?

The purpose of good assessment is to develop an accurate picture of your needs. This should help to indicate the most appropriate services to respond to those needs. Because different professions and agencies provide a range of services, assessment is usually done by more than one person in order to cover your health and social care needs. This means people need to consider the following:

- > Personal circumstances (including family and/or other carers).
- > Psychiatric symptoms and experiences.
- > Psychological thoughts and behaviours.
- > Physical health and well-being.
- > Social connections.
- > Housing circumstances.
- > Financial circumstances.
- > Occupation and activity.
- > Employment and training needs.
- > Risks and safety.
- > Drug and alcohol use.
- > Culture and ethnicity.
- > Gender and sexuality.
- > Spiritual needs.

- > People who depend on you.
- > Your hopes and aspirations.
- > Your strengths.

Assessment should also be based on what you want, not just on what services think they can provide. The 'unmet needs' (e.g. long waiting lists, such as for appropriate accommodation; services not easily accessible to all such as counselling) are important sources of information. They occasionally influence changes in thinking about what mental health services are providing as a priority.

A full assessment should be about what you can do, not just what you are unable to do. In this way it is equally as important to assess your strengths (i.e. abilities, achievements, qualities, interests, wants and wishes). It is your positive strengths that often help you to deal best with some of your needs and promote recovery.

Some of these assessments may be undertaken by one or two members of staff through one meeting with you, and the people who are important to you. Some assessments need the specialist attention of different people. However, your needs and strengths can change, so the reality is that assessment is a continuous process if it is to remain accurate.

#### What assessments are needed for care co-ordination?

Not everyone needs care co-ordination, because not everyone needs a number of different services working with them. If you are in contact with mental health services, through an in-patient unit or a community team, they will need to consider whether you need a care co-ordinator or not.

> Each local Mental Health NHS Trust will have a set of criteria to help them determine who needs care co-ordination and who doesn't at different times.

- > These are not secret lists, but it is also very difficult to describe every individual and how they change just in one short list of items.
- > What the word 'complex' means to you may be different to how other people see it.

So, these criteria should be used by the people providing services for you *flexibly*. They should take account of any changes in your circumstances and the impact they have on your life.

If you do have a care co-ordinator, one of the continuing assessments will be about when your circumstances change enough so that you no longer need a care co-ordinator. This would not necessarily mean you no longer need a service, but it should mean that your needs would be less complicated and need fewer people to meet them.

#### POINT 9:

Having a 'care co-ordinator' only means you have a number of different services to meet your needs. It is not meant to be seen as an entry ticket, or way of preventing access, to certain services.

#### Is the assessment really just about managing risk?

Assessing and managing risk is a part of everyday life both within and outside of mental health services. The assessment and subsequent care plan should be specifically about *your needs*.

> Risks that have been assessed should be discussed with you.

- > Any assessment in this area should also be asking you what your understanding and experiences of risk are.
- > You may prefer to talk about 'safety' rather than risk. It is your right to explain yourself in language that has more meaning for you.
- > The assessment will also, at times, be about the support you need when taking risks in order to achieve positive changes for yourself and others; as long as no deliberate acts of harm arise to you or others from taking such risks.

#### **POINT 10:**

We can all make our own assessments of our risk by asking ourselves a few pertinent questions:

- > What does 'risk' or 'safety' mean to you?
- > What risks affect you the most?
- > What makes you to feel more safe or less safe?
- > Who do you feel you can trust to discuss risk and safety with?
- > What could be done differently to reduce any risks?

# Can I make my own assessment of my needs?

Yes, the process of the CPA does encourage you to assess your own needs (your strengths and personal safety) including the use of any self-assessment tools you may be aware of.

#### **POINT 11:**

Use the list in this section (under comprehensive assessment), including strengths, to guide you to assessing your own needs and wants. Use any self-assessment tools you are aware of to help you. Discuss your self-assessment with the people who are important to you, and those providing you with a service.

# What is a Care Plan?

In its most simple form a care plan is what different people agree to do in response to your assessed needs. It then provides a document for discussing progress against your needs. Care plans should be drawn up for your benefit, not for that of the services, so you can be clear about what has been agreed and who will do what.

# Why do we need care plans?

We all get involved in some degree of planning in our daily lives, whether it is about going to appointments, visiting friends or family, what to watch on T.V. etc. The more complicated our way of living becomes the more we need to plan what we do. The same principle applies when responding to your health and social care needs. Services need plans in order to manage the complicated work they do and agreements they make.

- > It can be as simple as an appointment card detailing your next contact. It can be a letter from someone telling you how they intend to respond to any of your specific needs.
- > It can also be a much more detailed form that represents the discussion of a range of needs, and how they can be met by a range of services.
- > If you are allocated a care co-ordinator, then they will usually draw up a formalised care plan to co-ordinate the different services you require.

A care plan can be a good way of keeping providers of mental health services focused on what they said they would do in response to your needs. They can be a useful way for you to keep a check on what is happening to you. For you to be sure you are receiving the services that were promised in the ways that were agreed.

# Is the care plan just about the things I have problems with?

A care plan is essentially drawn up to manage the things you want or need to change in your life. This will usually be about problems and difficulties you are experiencing. However, it should recognise that often the best way you can change things is through doing more of what you are good at. This is about using more of your recognised abilities (using your strengths) to promote your recovery. A care plan can also include the support family and carers are offering you.

#### **POINT 12:**

The process of CPA is also about recognising what you are able to do, and what you want to do (using your strengths). In what ways is this (or should this be) happening for you?

### Will it be about agreed outcomes?

In most circumstances the care plan will document what has been discussed and agreed with you. It should also outline what you (and your carer) are agreeing to take responsibility for. It should not just be a statement of what services will do to you, or for you.

# What will happen in a crisis?

A care plan should also be about anticipating needs that might arise in the future, particularly if a mental health crisis emerges. Either on the same document or as a separate crisis plan, you and your carer should be clear about where to go or who to contact in crisis situations. You may have agreed the kind of triggers to watch out for, either to prevent a crisis from occurring, or to get earlier help or support. People providing services for you should also have some kind of contingency plan in place, which should inform you who you need to contact in

the event that your usual workers are unavailable. Good contingency planning can help prevent a crisis from happening.

Mental Health Services are not *emergency* services, and they are not designed to respond instantly to requests. However, it is generally recognised that a mental health crisis is something that can reasonably be responded to within a few hours. In the case of an *emergency*, where a response is needed *urgently/immediately*, there are other services that you can consider contacting.

#### **POINT 13:**

Have you given some consideration to what kind of crises you have experienced, or may experience in the future? What type of response would you hope for and who can you best discuss and plan this with?

# Can I make my own care plan?

Yes, the CPA process would fully support your wish to put together your own care plan, however complex your needs appear to be, or the number of services involved. It is one way in which you can have some control over saying what you want in response to your assessment of needs.

You may want to use Advance Statements as part of your care plan.

- > As the term suggests, these are written statements by you that set out, in advance, how you would like to be treated or supported in certain circumstances in the future.
- > They can include the details of family, carers and people who are important to you, who you may wish to be consulted in any decisions or care plans.

- > They can also set out, for example, what arrangements you want to have put in place for taking care of dependents or animals, or the safety of your property.
- > These need to be reasoned and discussed, but no services would tie themselves to statements that would be unreasonable in some circumstances. For example, you may not want medication or hospitalisation in the future, but no service could anticipate that there will never be a situation where medication or hospital would not be considered as an option.

You might also want to enquire into the use of *Direct Payments/Individual Budgets* as part of your own care plan.

- These are budgets held by Social Services Departments (across all disability groups) which offer more individual and personal ways of support, which put you more in control. In some situations this may also include employing people who you want providing support for you.
- > You can apply for these options to pay for specific ways you want a need to be met.
- > These can help you, and those who care for you, to think more creatively about ways of meeting your needs. This can be useful where the usual services are not able to respond in ways you want them to.
- > However, you will need to meet the eligibility criteria in order to use these.

You can ask your worker(s) for a blank copy of forms they use to document care plans if you wish. However, they may not always help you to describe what you want to do in the ways you want. If you aim to set out your own care plan, the things you need to think about and write down are:

- > Your assessment of your needs and strengths (from the previous section of this booklet).
- > What would best meet each of these needs (including using your identified strengths).
- > Who would be the best person to take responsibility for each task (with a date by which each should hopefully be done).
- > Any support your family, carers or other people who are important to you are willing to offer.

#### **POINT 14:**

The process of the CPA encourages you to take the lead in putting your care plan together. You should ask for whatever help you need in order that you have as much control of the process as possible.

# Can I opt out of a care plan?

The care plan should have been decided in agreement with you, and the people who are important to you. But it is your right to disagree with an assessment of your needs, and not sign something you do not agree with. It is important that you have the opportunity to write down the reasons why you do not agree. However, the service providers have a right to reason what they can and cannot do in particular circumstances, provided they are not excluding you from necessary services on improper or punitive grounds.

#### **POINT 15:**

If there is anything you do not agree with in a care plan you should firstly make your feelings known to the person who is putting the plan together.

# Do I need a different care plan with each person I see?

It is the intention through the changes to the CPA that one assessment and care plan should be able to follow you through the different contacts you have with services.

- > However, this does not take away the point that verbal arrangements and appointment cards with specific individuals are needed to respond to small changes in circumstances.
- Most importantly, you should not be expected to go through repeats of the same set of questions for the same aim with different people.

Bringing together a single assessment and care plan is something that will be more significant to those people experiencing 'more complex care co-ordination'. Achieving this will require the different services and agencies to communicate information and agree between themselves. It may also require your agreement for some agencies to share your information between them. It would also be useful for you to include family, carers and other people who are important to you, who you want to have information shared with.

# What is a Review?

Your personal needs, or perceptions of needs, change over time for many reasons. You can also make positive progress as a result of working closely with your carers and other people providing services for you.

- > Basically, a review is the means of checking on progress, and agreeing any changes to care plans.
- > It can just be you thinking by yourself about what has changed for you. Or it can be where people who are working together towards the same aims meet together for a discussion.
- > To some extent we are always reviewing progress every time we meet with the people who are providing services.

#### **POINT 16:**

Think back to the last time you remember discussing any type of progress in your life with someone else. What were you discussing, with whom, and how did the discussion take place?

# Why have so many meetings?

- > Meetings are the services way of organising their complex work. But they are not always your best way of expressing what you need and how things are going for you.
- > Services also organise meetings because it is the way they can sometimes make sure everyone is having a say about what they are doing or going to do.

# Do reviews always have to be in 'formal' meetings?

Some services claim that their way of doing reviews help you to have your say. They describe these meetings as being 'service user-centred' or 'person-centred'. However, many service users and carers express a view that they feel uncomfortable or even powerless in the type of formal meetings organised by services. So, the challenge should be to make reviews more service user-friendly.

- > It is about you, so you can ask your care co-ordinator to discuss your review with you in different ways, so you can be more comfortable and able to express your views and wishes.
- > It is also important that you are able to invite family, carers or people who are important to you to attend.
- > Where you receive services simply through one or two people, it may be easy to review progress as part of the normal pattern of contact with them (e.g. GP or Psychiatrist appointments).
- It does not always have to be a complex meeting. It can frequently happen within a 5-minute consultation or at the start or finish of a contact arranged for another purpose. The important thing is that you feel your needs have been addressed.
- > Even where service contacts are more complicated, requiring a care co-ordinator, they should still try to meet *your* preferred ways of discussing and reviewing progress.
- The responsibility should then fall to the care co-ordinator to represent your views and wishes to others involved in your care if other meetings are necessary between the different services.

# In what other ways could a review take place?

Even though a review will technically be a meeting, they can be different types of meeting. For example a review can be:

- > Part of a visit to your GP; by asking your care co-ordinator (if you need one), and/or carer, to join you as part of an extended appointment at the surgery.
- > By requesting a meeting of the different services at the GP surgery, at a time convenient to the surgery schedule.
- > You may just want to speak with one particular person you trust (probably the care co-ordinator) one-to-one. They could then represent your views at a professionals meeting, before bringing back a draft plan for your agreement.
- As part of your routine out-patient appointment with your Psychiatrist.
- > You may prefer to use an *Advocate* as your trusted representative.

The point is one of *flexibility*; and in this way a review can take many different forms depending on the imagination and agreement of you and the main people providing care and support.

#### **POINT 17:**

Reviews are meetings, but they do not have to be formal situations. They can take the form of more informal discussions if that is the way you express yourself more clearly.

# How much can I control my own reviews?

- > You should be able to choose where, when and with whom you wish to discuss progress.
- > Even where a date has been set for the next review you have the right to call an earlier discussion and/or meeting if you feel a strong need to do so.
- > However, where you agree to a full meeting you should recognise that a number of other service providers being involved makes these decisions a little more complicated to control.
- > The CPA process does support you to take on whatever level of control you feel able to achieve in setting the agenda and chairing such meetings.
- > The support of the care co-ordinator may help achieve these wishes more successfully.
- > A discussion with your care co-ordinator both before and after a formal meeting as part of your usual contact should help you feel supported and have control over the process.

#### **POINT 18:**

When thinking about how to make reviews more comfortable for you give consideration to:

- > Where it should take place (e.g. a service base, your home, or in a neutral place such as a café, park, etc)
- > Who do you want to be present at the review discussion (e.g. representatives of all services providing support to you, just the person you trust the most, your carer, an Advocate, etc)?
- > How do you want it to happen (e.g. as a formal meeting, as part of the normal contacts you have with your care co-ordinator, as a social event, etc)?

#### What role is there for an Advocate?

- > The process of CPA recognises your right to have an Advocate to support and/or represent you, wherever this will make the process easier for you to control and be involved in.
- > This would be a particularly important option if you feel they will be able to negotiate with groups of professionals more confidently than you can personally.
- > Alternatively, they could support you to conduct these negotiations yourself.

#### **POINT 19:**

Have you considered how to engage the services of an Advocate locally?

# What is the importance of setting dates for reviews?

In one respect, reviews are happening informally every time people meet together for whatever purpose. However, these discussions usually focus on very specific points that are important at that time.

- > The real value of reviews is about considering all of the aspects of your life that require some care and support. In this way you will be more able to recognise the fuller progress in line with what everyone has agreed to do.
- Without setting a point in time for a review, it becomes easy to get caught up in the detail of what is happening dayto-day.
- > The process of the CPA recognises that reviews should be held at least every year.
- > Where your needs are sufficiently complicated to require 'more complex care co-ordination', the frequency of meetings may be increased in line with what feels necessary.

#### **POINT 20:**

When did the last formal review happen? Is a date set for the next review? You and your carer(s) have the right to call a review sooner than planned if you need to.

# What can Carers Expect from the CPA?

# What rights do they have within the CPA?

The process of the CPA includes recognition that in many cases carers are providing valued and vitally important care and support, sometimes on a full-time basis. It also recognises that carers often feel cut-off from, and ill-informed about, the care of people close to them, even though they may be providing a significant level of care.

The CPA process sees people who are carers as 'partners in care', not just as a resource. They may also have different needs, views and expectations to service users and should therefore be considered separately, in their own right, rather than being tacked on to the service user's assessment and care plan. Care co-ordinators will be expected to listen to the views of carers, and to offer them appropriate means of assessing their own needs within their demanding caring role.

# How will carers be listened to, and by whom?

- > Ideally, the service user and carer(s) are working together for the same purposes.
- > In the majority of situations, service users agree to involving and informing the carer in all parts of their contact with services.
- > However, where service users do not agree to information being shared, carers still need to be listened to and supported by the care co-ordinator. This helps to establish a balanced picture of what is happening within the relationships, and to recognise the demands and impact of the caring role on them.
- > Care co-ordinators, and other providers of services, have a duty to explain the importance to service users of sharing

- information with carer's at all possible opportunities, and to signpost carers to information and support.
- > They should also signpost carers to their rights to help and support in circumstances when the care co-ordinator might be less able to provide the type of service required.

#### **POINT 21:**

Carers have a right to their own assessment of needs, and plan of support, including a choice about the level of support, a life outside of caring, regular breaks and support to maintain employment. Even where no care co-ordinator is involved, or the service user has no current contact with secondary mental health services, they have a right to an assessment of needs by the local council.

Confidentiality of service user information is vitally important, and their expressed wishes should be followed in the majority of situations. However, inquiries repeatedly show that in very rare events important information that carers tried to communicate was not listened to, and tragic consequences resulted. So, confidential information would also need to be passed on, in the rare circumstances, where the carer was deemed to be at some degree of risk.

If the carer is providing a significant level of care it is important that they have the level of information and any training they may need in order to support them in their caring role.

In the event that the providers of services are instructed by service users not to include or support recognised carers, the service providers should still signpost carers to other sources of help, and try to work with all concerned to improve the situation where possible.

#### **POINT 22:**

Carers should be provided with information about how to contact Adult Social Care for a carer's assessment in their own right, and local Advocacy or Carers groups.

# What about young carers (e.g. children of service users)?

The process of the CPA recognises that young carers, particularly children of service users, have very specific needs which should be responded to with great sensitivity. Whether or not they are providing a main caring role, they need to be recognised and given appropriate information and access to support. This needs to particularly help them to deal with the anxiety and feelings of responsibility that can develop about unexpected or threatening situations.

#### **POINT 23:**

Young carers need to be recognised and have direct access to service providers, and to other carers or specific young carers groups. This access should be there at all times, but you should expect a very rapid response in the event of a crisis. Attempts should always be made to identify young carers and assess the impact of their caring role, so they can be properly supported.

# What are Your Rights within the CPA?

# What does the CPA mean legally?

Your rights are about expectations, not about irrefutable legal rights. It is about informing you of what you should expect and ask for from people providing mental health services.

- > Under the Data Protection legislation you have a right to ask to see your records.
- > Signed documents, such as assessments and care plans, are legal documents in the eyes of the law, so you have a right to be represented accurately in them.
- > Where you believe statements to be inaccurate and potentially damaging to you, you should firstly discuss this with your care co-ordinator, or other main person providing services.
- > If this does not bring about the changes you feel are necessary to provide an accurate record, you have the option of engaging a solicitor to take up the case with the service or agency for you.

# What can I reasonably expect from the CPA by right?

It is about you getting what you need, within reason, from the people involved.

- > In this way the CPA declares your right to be treated with dignity and respect at all times. The right to be offered available information so you can make reasonable choices in your care and support.
- > It is not a right to have a care co-ordinator. The CPA is about the quality of *all* contacts with services, not just for people needing 'more complex care co-ordination'.

> The CPA is about your right to information, so that you are able to demand good practice.

In the event that these **principles** and **values** are not being delivered, or that you feel you are being denied a service through not being 'on' a level of CPA, you should in the first instance use the local arrangements for *complaints* procedures. This may include using an Advocate, or the services of a local service user/carer group. However, you are also encouraged to use local arrangements to register appropriate *compliments*... if you find the CPA process useful, please feed this back to service providers so they can know what is working.

#### **POINT 24:**

The Care Programme Approach (CPA) is not an 'event', that just happens in the form of administrative meetings, in order to ration the services provided.

The CPA is a 'process', guided by principles and values, that describe what good practice should look like in the delivery of all mental health services.

#### **POINT 25:**

# The following are useful national contact numbers (for more information):

Department of Health: Customer Service Centre 020 7210 4850 (9am–5pm, Monday to Friday)

MIND *infoline* 0845 766 0163 (9.15am–5.15pm, Monday to Friday)

Saneline: Crisis Line 0845 767 8000 (12 noon to 2am, everyday)

Rethink's National Advice Service 020 8974 6814 (10am–3pm, Monday to Friday, except Tuesday and Thursday 10am–1pm)

For more national advice lines log on to http://www.helplines.org.uk/MH\_members.htm

Ask your care co-ordinator or main person working with you for details of local contact numbers.



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