Book Section:

Psychiatric & Mental Health Nursing 3E - Chapter 15

Conducting Family Assessment

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Introduction

There is a growing awareness that a person's recovery from mental illness is largely dependent upon the informal support they receive. Yet when people experience mental illness most families, friends and carers are unaware of mental illness or how to cope with it[1]. Consequently this sense of powerlessness reduces coping strategies; increases social isolation and has been found to cause depression and physical health problems[2]

Family carers offer governments a low cost way to support people with long term health conditions. Public services could not function without the massive contribution they make. The latest figure (£119bn) this input saves the country is quoted by the Carers UK[3] to be three times the UK's defence budget. This figure has risen almost 40%, since 2007 when the value of carers' input was put at £87bn; a clear sign of the growing number of families who are taking on caring responsibilities. Government Census data released in December 2012 revealed the greatest rise has been among those providing over 20 hours care the point at which caring starts to significantly impact on the carer's health and wellbeing.

Over the last 50 years health care delivery has changed significantly; people with mental health problems increasingly undergo treatment in their homes, with families and informal carers playing a pivotal role. This responsibility is set to increase. For this reason it is important to assess what support systems people have, ascertain whether informal caregivers have the resources to provide care and to prevent serious health problems identify ways to support care giver health and wellbeing.

Learning outcomes

By the end of this chapter readers will have had the opportunity to:

1. Consider who is a carer and what impact mental illness can have on families
2. Appraise the implementation of Care Act 2015 as this will increase the expectations in terms of identifying carers and offering assessments to a wider group of carers who will become eligible for the first time.
3. Examine information sharing protocols
4. Identify evidence-based assessment tools
5. Critique the tools data, analyse and use the findings to support family inclusion within multidisciplinary team decision making
6. **Consider ways to incorporate assessment strategies in clinical practice**

Background

Decommissioning of psychiatric beds and the promotion of community care has been sanctioned for over 50 years. During this period the majority of home based care has been undertaken by informal carers and family members. There has been recognition of the value of this informal role, yet empirical research also identified family factors can influence peoples relapse rates, illness course and outcome[4]. People living amongst families and informal carers in high levels of criticism or over-involvement tended to have poorer outcomes then those exposed to warm, appreciative attributes, positive interaction patterns and coping strategies[5]. Unfortunately, some professionals have unwittingly used this evidence to promote negative attitudes toward families. In recent years however an attitudinal shift has occurred; family intervention studies have equipped more professionals to provide therapeutic interventions and work proactively with families to enhance their coping skills and increase their wellbeing.[6] Indeed, from their onset some training programmes promoted service users and carers as valuable members of curriculum development and teaching teams [7]

Training together and sharing coping strategies supported partnership ideologies and professionals are now in stronger position to comprehend the maelstrom of problems families encounter. However, away from the research and mental health teaching environments, mental illness remains outside most people's experience. When mental illness does occur families can feel shocked, confused and isolated. The world they enter is frightening and the rules are unknown. Families are often still left to cope alone for long periods. The time of greatest need is the time when families have the least knowledge and information. Information and communication is often inadequate or hit and miss, some families never get adequate support, don't recognise when they need it or know they have needs and rights to support, information and involvement.

> *"They used lots of term I didn't understand. I couldn't keep asking what it meant because I felt stupid"*   *Jane, Mother*

> *"When my Dad was terminally ill in general hospital I was treated with compassion. When my husband was admitted to a mental health ward I was turned away" Dee, Partner*

> *"It was critical for my own health to be able to access services. The information on what can be provided is really valuable; after five years of supporting my wife I have only just learnt I can apply for a carers respite grant which has been wonderful"*   *Brian, Husband*

Carer Definition

The definition of an informal 'carer' varies according to context. Carers' organisations' and advocates usually use the term broadly to mean anyone providing unpaid care and support to a person with a disability, illness, frailty or other problems in coping with daily life. In order to be eligible for funded carers' support, current legislation (that guides local authority assessments of need and provision of services), carers generally are required to show they provide 'substantial and regular' care. They need to request an assessment from a local authority (or a NHS Trust with delegated social care responsibilities) and then have their eligibility for funded services or other support assessed against local criteria.

The Care Act 2014, which will be introduced from April 2015, makes more provisions for carers and recognises their needs more comprehensively[8]. This means two significant changes to the current law on carers' assessments.

- It removes the requirement for the carer to actively ask for an assessment (i.e. it should be offered as routine)
- It removes the requirement for the carer to be providing substantial care on a regular basis. Instead, the only requirement is that the carer 'may have needs for support – whether currently or in the future'.
- If both parties agree, the Care Act allows for joint assessments of service users' and carers' needs, enabling more sensible and personalised family or couple based support arrangements.

Carers are usually not charged for the services they receive, but local authorities can charge under the Care Act. If deemed eligible, carers can receive personal budgets and direct payments in their own right, just like service users. Carers can also be provided with support through additional services being provided to the person they care for.

Young carers (under 18) are eligible for support under children and families legislation, as are parent carers of disabled children. However, the Care Act will enable parents of people approaching 18 to receive earlier assessments of their needs (and the needs of the young person) to improve transition to adult services.

> **Christine's Reflections**
> *As a family carer, I support a relative and a friend who have schizophrenia. I am a volunteer and activist in mental health, focusing particularly on families and carers' issues. In this role I help to facilitate a carers' support group and train mental health staff to engage with families and support them effectively.*
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> *It is for aforementioned reasons that it possible to recognise Carers come from all walks of life, income-groups and ages – the quotes I use from other family members in these reflective sections will highlight this. They are parents, grandparents, step-parents, partners, siblings, sons, daughters and friends. The people they care for are some of the most vulnerable - the least able to speak up for themselves. Family members are sometimes reluctant to identify themselves as "carers" as they see the role as part of their "normal" family responsibilities. They may be slow to recognise that they have needs of their own which are distinct and separate from those of their relative.*
>
> *It is essential to encourage people to identify themselves, as this gives them rights, entitlements under carers' legislation and access to support to meet their own needs. However, it is also essential to recognise that there is a strong, continuing overlap with the needs and wellbeing of the service user.*
>
> *"Carer" or "family member"*
>
> *We tend to think in terms of "the service user" and "the carer". But severe mental illness affects the whole family. Family members often react in different ways to their relative's illness and the illness impacts in different ways. Everyone in the family has their own individual needs and strengths and, is on their own path towards recovery, as well as supporting their relative. Understanding the nature of relationships and interactions within families is key to working supportively with them*

What implications do you think the Care Act will have?

The care act 2014 is an important step forward. It gives carers a clear right to receive services, and places new duties on social services to identify carers and assess their needs. Its aims include better integration of health and social care, provision of information, advocacy and advice about carers' services, with an emphasis on well-being and prevention, which should help carers to receive support early. Consistent, national criteria will be established for assessing carers' eligibility to receive services and support. These aspirations are very welcome.

All this comes at a time of diminishing resources for social services. How will it work in practice? Whilst there is a new and important duty to offer all carers an assessment of their needs, this does not guarantee that an increased number of carers will be assessed as eligible, as resources are scarce.

Mental health carers sometimes feel that generic carers' assessments are geared more towards those with physical conditions and personal care needs than to the specific needs of mental health carers. It will be important, and could be quite challenging, to ensure that mental health issues are adequately assessed, and that the new system does not, unintentionally, disadvantage mental health carers. I think carers' perception of the purpose of the carers assessment might change if it is regarded, or presented to them, much more as a test of eligibility than was formerly the case.

There may be a need to consider how to support carers and families in their caring role, irrespective of whether or not they are assessed as "eligible" for social services support under the Care Act. There may be carers who are not assessed as eligible for services in their own right, but still have considerable needs in their caring role

Meeting carers' needs within the NHS

NHS Trusts have a broad range of responsibilities towards carers, families and friends. NHS organisations and those who work in them are responsible for ensuring carers are involved optimally in service user assessments, care and crisis plans, reviews and risk management. NICE Guidance 2014 recommends that NHS Trusts provide psychosocial interventions to families, including the person using services where appropriate to support them to be able to live well together and to help reduce stressors and causes of tension or conflict. There are also specialist family therapy services available which may be able to support carers and family members alongside the service user. Trusts should also provide support, advice and guidance to individuals and to groups of carers, often in relation to specific conditions or needs groups. Where Trust have delegated responsibility for social care functions, staff are tasked with identifying and providing assessments, advice, information and services to carers – currently specifically 'substantial and regular' carers, but this will widen under the 2015 Care Act as described above.

Overall, caregiving should be recognised as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue, financial hardship, and changes in social relationships. They may also experience physical health problems[9]. Perceived caregiver strain has been associated with premature institutionalization for care recipients along with reports of unmet needs. Assessment

processes are, therefore a useful way to identify families who would benefit from a more comprehensive understanding of their caregiving experiences in terms of:

- Identify individual & carers' experience, expertise & knowledge in terms of stresses, concerns and coping styles
- Developing shared understanding of needs, support plans and strengths to build on
- Providing recognition, help & support for their caring role

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Christine's Reflections

Why family assessments are important

I can't underestimate the importance to family members and carers of being listened to, having their experiences and contributions to their relatives' care, their needs and strengths acknowledged, understood and valued. It is essential to establish the level and amount of caring families are able to provide. Understanding the carers' and families' pathway is absolutely fundamental. This is well articulated by Mohr et al (2000) as "the three stages of caring" which describes the family's experience from the initial shock and bewilderment following a psychotic episode to the point where things are start to fall into place, the family acquires coping skills and gains knowledge and confidence.

You will find that, at every stage, families have different needs and strengths, different levels of knowledge and understanding of their relative's illness. Be supportive and non-judgemental in your approach. Families are often vulnerable, at a low ebb which can make them over-sensitive to remarks which they might perceive as criticism. For this reason attitude towards assessments is sometimes ambivalent. Although we desperately want our voices to be heard and needs understood, some people find the term "assessment" intimidating and off-putting, particularly if they feel that their own abilities are being assessed. Too often a carer's assessment feels like a tick-box exercise, which does not produce useful outcomes and when this happens carers lose confidence in the process.

I think it is important for staff and family members, to make a clear distinction between the generic carers assessment which is required by legislation (the Care Act) and which is "owned" primarily by social services, and the more in-depth family assessments which focus on the family's understanding of mental illness, their need for information and support.

*Mental health carers often comment that generic carers' assessments are structured more towards carers of people with physical health and personal care needs, rather than to the needs of mental health carers. The kinds of support available (eg respite care) are not always appropriate for mental health carers. There is a focus on providing "carers services" perhaps at the expense of building capacity in the care-giving role. It is very important that the health or social care professional is attuned to mental health issues, and works constructively with the family carer to ensure that the assessment is relevant to their situation. The generic carers assessment can then signpost the family towards a more in-depth assessment**.***

Assessment Process

> *"Caregiver assessment is a systematic process of gathering information about a*
> *caregiving situation to identify the specific problems, needs, strengths and*

resources of the family care giver, as well as the ability of the caregiver to contribute to the needs of the care recipient" [10]

Appraising a family's needs and undertaking a carer's assessment is often perceived by professionals as difficult, because the process is too time consuming, is not within their competence or being within the domain of another profession[11].   To add to the challenge of knowing who to assess and when Mohr et al (2000) suggest families' experiences fluctuate; they are individuals on their own journey recovering from agonising trauma. As they move through catastrophic events, learn to cope with guilt, resentment and anger to becoming advocates, in many ways they become their own worst enemy [12] . Each member is recovering differently, going through different stages at different times and there is no guarantee that they will get to the end of the journey together or in agreement that their management style worked.   Indeed, most recall stories of muddling through, roller coasters and use phrases like "blind leading blind". Caring for somebody with a SMI can become all consuming. Family members can start to normalise some very odd behaviours, shut the door on friends and stop having a life of their own.

Understanding where family members are on this experience continuum often leaves practitioners unclear about when or whom to engage with[13] and researchers being disappointed by the difficulty in engaging carers into programmes offering help[14].   Recent investigations into the support needs of siblings have also revealed a need to enhance siblings' knowledge about psychosis and their coping capacity, thus potentially improving their own mental wellbeing and promoting their contribution to service users' recovery[15].   To add to this conundrum is how professionals should provide these alternative services, share information and overcome issues of confidentiality.

Information Sharing Protocols

The beneficial effects of including family members in the planning and treatment of people with mental health problems will be reinforced throughout this chapter. Indeed, since the Carers and Disabled Children's Act was passed[16] carers have had a right to have their needs assessed and professionals should support them in their caring role. Despite this recognition, the carers need for information has to be balanced with a service user's right to privacy.

Ethical dilemmas and confidentiality issues are frequently encountered in everyday practice, it is therefore important to consider potential factors which may promote or hinder information sharing processes. Indeed despite knowing that families can play a significant role, many professionals remain uncertain about how to share understanding or address their needs routinely; hence why many families report feeling undervalued and being left out of the communication loop.

For those working within child and adolescence services, with older age groups or who have experience of working with families, this dilemma doesn't appear to be as prevalent. In these service areas, because family inclusion is more common place, they are more likely to be perceived as allies, so some sort of respectful contact is usually possible.   However, when an adult of working age withholds their consent, even if the family appear crucial in helping someone achieve their recovery goals, breaching individuals rights to confidentiality is commonly mentioned as an engagement barrier[17]

Until recently there has been a lack of research in this area. To address concerns consistently raised by families,[18] assessed mental health sharing practices across the UK. Three groups informed the multiple method design: a core research group, an expert panel and a virtual electronic panel, all had service user, carer, professional, support worker and academic representation. Qualitative interviews of 24 participants were used to assess involvement in mental health, how confidentiality affected roles; where information sharing worked well and how information sharing could be improved. Data was also synthesised from policy reviews, survey of current practice and qualitative interviews. The study identified 56 policies and 35 supporting documents but only 5 provided any practical guidelines on how to share information. The overall review of these policies highlighted that those co-authored with carer groups advocated the use of advance statements to record preferences of whom should be involved at during relapse or times of crisis. The national survey of current practice included service users (n=91), carers (n=329) and professionals (n=175). The majority of the carer sample reported they were well supported in terms of access to general information. However when asked about the reasons why professionals did not share personal information, 47 (28%) reported confidentiality was given as the reason. The majority 57 (35%) carer respondents reported they had not been asked for it; 35 (21%) service users did not provide consent, were unable to give it 9 (5%) or were not asked to provide it 32 (19%). Examples, given ranged from service users provide consent and changes mind, language barriers to carer is not next of kin. Service users (n=91) more than half stated their families should have access to personal information and 47 (55%) were comfortable if their carer were involved and 47 (55%) stated they should be offered separate support from professionals.

Overall, the study helped to highlight the value of mental health professional having a positive, inclusive attitude towards families and taking a proactive role in engaging them. In this way they are more likely to be able to influence multidisciplinary decision-making. To achieve this goal Slade et al (2007)[18] concluded information sharing good practice principles involve:

	Carers	Service Users	Professionals
Good Practice Principles	Explain to service users about the carers 'need to know' Seek information/support from another professional source	Consent must be obtained before information is shared	Collect consent Establish effective communication and maintain dialogue
	More consultation and improve professionals attitudes	Identify information person feels comfortable sharing	Acknowledge distress and recognise the carers role and their rights
	Attend care planning meetings	Use an advocate or support network	Share information on a general (hypothetical) basis
	Identify need through carer assessment process	Consider long term relationships before deciding to share information	Talk to carers about confidentiality and professional codes of conduct
In cases of serious disagreement, carers, service users and professionals should use framework for best clinical practice (see figure 3)			

Christine's reflections

Confidentiality and information sharing are hugely important. Carers are well aware of the complex ethical dilemmas that can arise. Getting it right makes a tremendous difference to the service user's recovery and their carers and families' well-being and peace of mind. If handled badly, this can cause more distress and anguish than almost anything else.

For the family, it cuts both ways – we want to receive sufficient information about our relative's illness and treatment to help us support their recovery. Equally important we want to give mental health professionals information about what we know about our relative and what we observe when they become unwell, so that we can help them, and at times, our rights to confidentiality need to be protected.

Service users often turn away from their carer or family when they become ill, just at the time when everyone could benefit most from sharing information - and this situation can seem difficult or impossible to resolve.

What can we do to overcome barriers to communication?

The basic principles are outlined. We can apply these to ensure that families are appropriately included in care plans, relapse and crisis plans. It is very important for a professional to revisit these issues regularly as the service user's and their family's needs change.

There is some information that we all need to share; there are issues which are personal and private to the service user and, equally so for carers and family member. For me, the key to all this is for the mental health professional to support the family to set its own "ground rules" which encourage good communication, but also respect everyone's need for some privacy. We should always remember that the aim is recovery, and the greatest possible independence and self management for the service user.

METHODS OF ASSESSMENT

Interpersonal skills

An important part of the engagement process is an in-depth appraisal of family's experiences, perspectives and needs. There are a variety of different methods to undertake this task. The first would be to listen. The opportunity to "share their narrative" is widely acknowledged to be of powerful benefit to families who may have struggled to access appropriate help [19]. Indeed, although families' experiences have common themes, individual involvement in mental health services will be different. To avoid making judgements or painting everyone's experience with the same brush, it is therefore important to consider the skills and attributes required to assess and work with family's needs.

A small number of studies [20] [21] [22] have provided an overview of what qualitative personal qualities and interpersonal characteristics may be "helpful", such as being able to create a calm atmosphere, the ability to listen, being non-judgemental, helpful and interested. Finding something likable about the family really helps and listening to family's narratives is the first step in achieving this. Most families want to talk about what has happened and this process can provide a platform to obtain a family history and facilitate a background discussion about familial relationships, who is involved and supporting whom. From the example (see figure 1) it is possible to determine that Jane has one sister (females are represented as circles), who is married with one daughter (Jane's Niece). Jane's parents are still alive, her father (males are represented as squares) has two brothers and her mother has a

sister. Her paternal grandmother has died (as the circle contains an X) and so has her maternal grandfather. Jane is separated (illustrated by the line through) and has no children. The development of this genogram provided a first hypothesis regarding stress vulnerability (see chp ..) and what may have exacerbated Jane's second psychotic experience. She had commenced divorce proceedings and family arguments about this decision meant Jane no longer felt welcome in her parents' home.

PLACE FIGURE ONE HERE

Figure 1
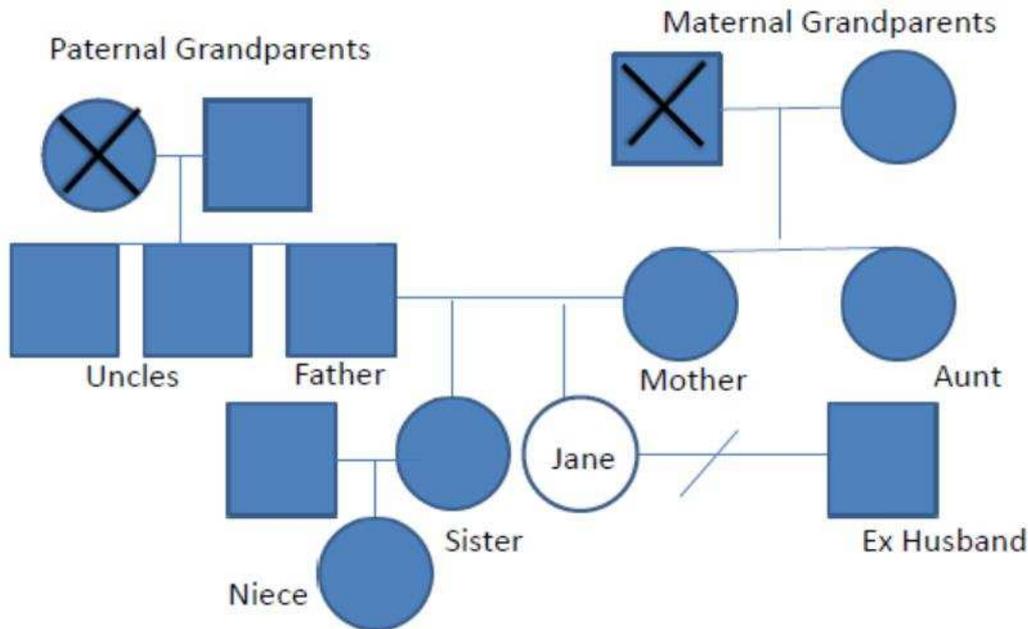
The assessment process can provide direction. Post genogram discussion and development the next step would be to facilitate a formal appraisal of family need [23]. Outcome orientated assessments encapsulate the extent to which interventions do what they are intended to do. Some may consider 'form filling' to be a barrier to engagement especially if families' competence to care is felt to be under scrutiny, the tools used are lengthy or they are perceived to have little value when the process results in little or no action. However, the assumption that all carers will feel bombarded has to be reviewed. Clinical experience suggests that many carers perceive formal assessment approaches as a refreshing change.

It can be very reassuring when sound, practical interviewing and rating procedures are therapeutically utilized, since this process demonstrates that assumptions are not being made, that accurate observations are sought and that systematic procedures to identify appropriate interventions are being followed (see figure two). Indeed information obtained via systematic assessments at baseline, mid and post- intervention provides clear evidence that change can occur (see table below for examples).

Assessment Name and Reference	Assesses	Synopsis

Carer Strain Index (CSI) Robinson (1983)[24]	Caregiver strain amongst long-term family caregivers. Self-Report can be left with family for them to complete & return Originally developed for carers of older adults	Contains 13-questions that measure strain related to care provision: Financial, Physical, Psychological, Social and Personal. Can be used to assess individuals of any age who have assumed the caregiving role
Carers' Assessment of Difficulty Index (CADI) Nolan et al (2003) [25]	Difficult experiences and stressors Self-Report can be left with family for them to complete & return	Contains 30 statements made by carers regarding the difficulties they experience & how stressful they find it.
Carers' Assessment of Management Index (CAMI) Nolan et al (1995)[26]	Coping, stressors and management styles. Originally developed for carers of those with dementia and learning disability	Contains 38 statements which carers have made about the coping strategies they use & how helpful they find them. Builds on carer strengths and provides a baseline for engagement discussion.
Experience of Care Giving Inventory (ECI) Szmukler et al (1996)[27]	Difficulties, burden and coping Self-Report can be left with family for them to complete & return	66 questions cover 10 domains first eight described as negative i.e. Difficult behaviours; stigma; problems with services etc. The other two focus on

		positive areas such as personal experiences and relationships. Useful engagement discussion tool that provides a baseline to direct intervention
Carers and users expectations of services: Carers version (CUES-C) Lelliot et al (2003) [28]	Service Expectation Can be used as a supplement to others described or as a standalone, to facilitate discussion and as a baseline to direct intervention.	Self-rated 13 item questionnaires, which addresses areas such as how to get help, information about care worker, information about the illness; involvement in planning of treatment, relationships; well-being; risk and safety.
Knowledge about schizophrenia interview (KASI). Barrowclough & Tarrier (1995) [29]	Understanding of schizophrenia Can act as a follow up for RAI or as a standalone. Old terminology use but helps to formulate development of psycho education packages.	Examines cause, prognosis, symptoms, medication and management,
Relatives Assessment Interview (RAI) Barrowclough & Tarrier (1995) [30]	Global assessment Used to obtain information to help direct family intervention.	Covers seven key areas, such as: client's family background, contact time, current problems and effects of the illness on the carer.
Family Problems Questionnaire (FPQ) Morosini et al (1991)	Objective and subjective burden	Contains 29 items that focus on burden, support received by professionals and from members of social networks

Family Coping Questionnaire (FCQ) Magliano et al (1996)	Global assessment of coping styles	Self-administered 34 item questionnaire divided into sub scales Information, Positive communication, maintenance of social interest, patients social involvement, use of drugs and alcohol, collusive reactions, non compliance to prescribed treatments , search for spiritual guidance and talking with friends.

Overall, the family assessment process is valuable because:

- Assessment tools can be selected to meet families' specific needs
- Being familiar with the tools enables practitioners to administer them sensitively and interpret wisely.
- Assumptions about how to intervene are less likely to be made.

Case study to illustrate family assessment process

Charlie, aged 26 had experienced three major psychotic relapses, resulting in admission. On the third occasion, his mother, Sarah who had never been included in Charlie's care or participated in a carer's assessment contacted staff for more information. To address this service provision deficit, initial contact was made though Charlie's care coordinator during a Care Programme Approach (CPA) review. This CPA highlighted the need to recognise the supportive caring role his mother played but also to ensure that Charlie's psychosis was treated more effectively. The care coordinator gained Charlie's consent (see confidentiality case study) to formally meet Sarah and other members of his family to share understanding, collate experiences (as highlighted in box 1) and assess their support needs.

BOX ONE: Assessing Experience & Expertise (Gamble and Brennan 2006)	
Service User	Impact of symptoms Treatment effects Strengths in functioning Knowledge & understanding of family culture and values History of experiences
Carers	Early warning signs Assessment of stress

	Knowledge & understanding of family culture, history and social support networks
	Resource to support service users recovery goals
Professionals	Knowledge of treatment strategies
	Advocating within system
	Illness effects on wider population
	Interventions to increase coping strategies, reduce stress & burden
	Signposting to non-statutory support agencies and peer support networks

This process involved meeting family members individually to gain their individual perspectives and understanding. Charlie had two sisters, his father often worked away from home and he described his maternal aunt as playing a significant role in the family. Whilst generating a genogram (see genogram illustration for explanation) concerns were raised about how to find sufficient time to meet everyone. For this reason a number of assessment strategies were chosen. Charlie's siblings were asked to complete a CSI, his aunt and father a CUES-C. Whilst the care coordinator and his mother completed a RAI together, Sarah expressed delight at doing the assessment at a mutually convenient time at home, as she stated the expectation had previously been for her to "attend inconvenient office hours based sessions".

Having collated these baseline assessments, it was possible to summarise the family needs as:

Wanting more information about

- what each professional's role and responsibilities were and whom to contact when
- crisis planning
- psychosis, treatment approaches and how to anticipate relapse
- dealing with Charlie's demands for money, perceived lack of motivation and concentration
- how to cope, stay on good terms, maintain personal activities and access social support networks

And, use outcomes to construct a rationale for integrating family work into Charlie's routine care, as family meetings would:

1. Increase their knowledge and understanding of psychosis, including raising their awareness of early warning signs and strategies to proactively address them.
2. Promote communication between family members, re-establish relationships (especially with Charlie's siblings) and enhance working alliances with professionals
3. Build on the families' strengths and increase everyone's problem solving skills and coping strategies.
4. To address ways to overcome obstacles preventing independence and life goals being achieved.

The results of these assessments were also drawn upon to formulate an integrated care package, which could be monitored over time. Goals for future interventions with Charlie included:

- Activity scheduling and individual problem solving to increase his motivation, activity levels, social and independent living skills.

- Cognitive therapy for voice hearing, utilising, for example, coping strategy enhancement techniques.

- Assessing side effects and examining Charlie's motivations to continue to take prescribed medication

Involving family and friends in medicines management

Like many others, Charlie's family were integral to his treatment and recovery. Yet, professionals often exclude them from discussion about pharmaceutical treatments and especially side effects. Medication conflict can feature highly within families, many have conflicting beliefs about its value and purpose are ill-prepared to take on a dispensary role and service users dislike the attention (Harris, Baker and Gray, 2009). Unwittingly, family members can be perceived as agents of control, so requests to adhere to treatment are either ignored or provoke tension. However, families can offer a wealth of information about past treatment failures and successes, they often monitor an individual's treatment adherence and are a reliable source of determining relapse. This knowledge can only be obtained when they are actively involved in an assessment process. Although it is widely known that carer's feel excluded from services (see information sharing protocols section) and receive limited education/information provision particularly about medicines. For some families developing the confidence and skills to take an active part in treatment decisions may take some time. Family intervention can support this competency development, in this way carers are more likely to be able to highlight significant life events from treatment decisions and be involved in care plan discussions around medicines and treatment.

Collaboratively working is about open and honestly sharing information, and ensuring full discussions on aspects that are important to the service user. People should feel active partners in treatment decisions and have influence regarding the frequency and format of treatment reviews.

Sharing and giving information about medication

Information sharing with service users and carers is notoriously poor. Carers have been asking for clear, unbiased information about medicines for some time. Information sheets provided with medicine are often inadequate or unclear. Without this information families can on occasions attribute side effects of medication to a person's illness. Certainly key issues which cause tension within families for example, weight gain, sexual dysfunction; lack of motivation can all be side effects. Without proper knowledge service users and their families can be powerless to modify behaviours, encourage alternatives or develop a healthier lifestyle.

Promoting knowledge and understanding about psychotropic medication and treatment influences with an individual and family will mean they become a more active part in treatment decisions. As part of a family intervention package it's useful to have meaningful discussions about diagnosis and pharmacological treatments. What are the families' views, knowledge and past experiences of psychotropic medicines, including dosage and circumstances? These views are often the most important factor of adherence. Indeed, without sensitivity aspects of treatment and culture can exacerbate engagement barriers particularly those from black and ethnic minority families.

> *"Black and ethnic families are very distrusting of services. Having been in mental health for so long I can understand why. There is something about stigma. They are frightened to share information in case they are prejudged" Carer support worker 2 (Slade et al 2007).*

This carer support workers observations replicate what is consistently reportedly; the UK African-Caribbean population are diagnosed with schizophrenia than any other ethnic group and are more likely to access psychiatric services via the police and under compulsion. The Aesop study in 3 cities (London, Nottingham, and Bristol) reported it takes African Caribbean people longer to obtain a diagnosis and when they do receive treatment this usually involves higher doses of medication and limited or no access to psychological therapies, such as family therapy (Morgan et al 2008).

The CaFI project is investigating the implementation and acceptability of a cultural adaptation of Family Intervention for African Caribbean's (Edge, 2014). Therefore, until these findings have been published Harris et al (2009) highlight some useful exercises to aid families understanding and decision-making around treatment and help them when meeting prescribers.

Family decision-making around treatment	Meeting Prescribers
Looking back – doing a timeline Checking out familial beliefs about treatment Assessing and enhancing the person's ability to take medication, and the carer's ability to support medication taking Checking the pros and cons of medication Looking forward Working with beliefs about medication Evaluating the service user's and carer's experience of medication Addressing consent and planning for crisis Constructing Advanced Directive, wishes, enabling carers to provide an intention of involvement at times of crisis or relapse	Identify the objectives Rehearse the points you want to get across Write things down (take notes) List the questions Share Advance directive and crisis plan arrangement

Overall, the family can play an important role in monitoring side effects, particularly those which may influence the dynamics within a close relationship ie. Sexual dysfunction or weight gain. The importance of the family helping maintain good physical health cannot be underestimated.

Working with people and their families to derive maximum benefit from medicines takes skill and knowledge. Many medication management education programmes have been developed, incorporating supervision, and practitioners would be advised to access training in this area for further knowledge in this area see Harris et al 2009.

Christine's Final Reflections

- "Think family" and work supportively with carers in this way everyone benefits; most of all, the person with mental health problems.
- Working collaboratively with the family and building their capacity to support their relative makes *your* job easier as well as theirs.

Because we are much more used to working with patients as individuals, working with the family may seem rather difficult and daunting. As this chapter points out this requires skills and knowledge.

These are all skills that everyone can learn, techniques that are tried and tested and a range of tools that everyone can acquire and use (including, of course, family members themselves).

Many service users lose close contact with their families – often, sadly, the illness itself has driven the family apart. Too often mental health professionals just accept this as the norm. I would like mental health professionals to do much more to encourage and support service users to stay in touch with their family because there are such clear and obvious advantages for everyone if the family is involved.   This chapter provides the practical guidance to help you with this.

Although families share broadly the same issues, every family's experience, and everyone's story is different and individual. Their needs and, equally important, their strengths may not be immediately apparent. This is why sensitive assessment is so important, followed up with collaborative work, which supports their needs and plays to their strengths.

This chapter has discussed issues which are fundamentally important for families and carers. In particular information sharing (confidentiality), medicines management and sharing family decision-making. If you can get these right families' lives are transformed.

"I feel so much better. I have learnt how to talk to my daughter. I made a lot of mistakes and sometimes still do. Now I am more confident and relaxed and this is helping my daughter in her recovery."   *Sunita, parent.*

Recommended Reading

Lobban, F., Barrowclough, C (2009) A Casebook of Family Interventions for Psychosis. John Wiley and Sons Ltd: Chichester ISBN 978-0-470-02707-3

This readable, user friendly guide to family intervention discusses family needs and illustrates different interventions approaches. It outlines how to tailor family interventions to meet different needs e.g. working via interpreter or with families in which multiple members suffer mental health problems.

Smith, G., Gregory, K., Higgs, A. An Integrated Approach to Family Work for Psychosis: A Manual for Family Workers. Jessica Kingsley: 2007

This manual for working with families of people with severe mental illness discusses what constitutes family work, when it might be offered, and how and where it might be applied. The book addressed both theory and practice, and concentrates on the experience of mental illness for the service user and their family, providing a focus for intervention.

Useful websites

Meridan family work programme http://www.meridenfamilyprogramme.com/

Within this site you will find useful information and resources if you are a person living with mental health issues, a carer, family member, friend, mental health professional or commissioner.

Rethink Mental Illness http://www.rethink.org/home

Helps people living with conditions like schizophrenia, bipolar disorder, personality disorders and more to recover a better quality of life.

Provides a excellent resource to support siblings and introduce them to Siblings Network.
http://www.rethink.org/carers-family-friends/brothers-and-sisters-siblings-network

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