

# People with a psychotic illness and a physical condition

The combination of psychosis and chronic physical disease poses difficult management problems for patients and their carers. Insulin-dependent diabetes, for example, requires strict adherence to a diet and to a medication regime. If there are already difficulties with adherence to an antipsychotic regime, these are exacerbated by the additional strictures of the treatment for diabetes. Furthermore, the weight gain caused by some antipsychotic drugs is antipathetic to the control of the diabetes and hypo- and hyperglycaemic episodes can complicate the psychiatric picture. The side-effect of weight gain is of particular significance to patients who have an eating disorder in addition to schizophrenia. It is noteworthy that one study has demonstrated a relationship between high expressed emotion in the carer and poor control of diabetes (Koenigsberg *et al*, 1993). Thus the outcome of both the psychiatric and the physical condition may be improved by family work.

It is not uncommon to encounter psychosis and learning difficulties in the same individual. When people with schizophrenia make a first contact with the psychiatric services their IQ is found to be between 87 and 89 on average. This suggests a drop in their IQ over the preceding period, which is supported by a falling-off in academic performance that often occurs in the early teenage years before the overt appearance of psychotic symptoms. We are not concerned with this phenomenon here but with learning difficulties that become evident in early childhood. The combination of learning difficulties with psychosis is particularly likely to engender overinvolved attitudes in carers: both family members and professionals. Mothers tend to become overprotective towards a young child with learning difficulties, although it may be difficult for an observer to judge what an appropriate level of protection should be. When a person with learning difficulties develops a psychotic illness, a mother with overinvolved attitudes is almost bound to intensify these.

Sensory defects in a person with a psychotic illness are particularly difficult to manage. Impairment of hearing or vision requires the care of

specialists in these areas of medicine and cooperation by the patient in accepting remedial action. Paranoid delusions can be exacerbated if patients with impaired hearing fail to wear their hearing aid. Patients with impaired vision can endanger themselves or others if they do not heed professional advice concerning the precautions they need to take.

It is far from easy to achieve a smooth liaison between the various agencies dealing with the different aspects of the patient's well-being. Specialised services tend to be segregated from each other. Even bringing together a service for learning difficulties and one for psychosis can require considerable sustained efforts.

## **Family 4. Alicia Hammond**

### *History*

Alicia is aged 26 and has suffered from schizophrenia from the age of 12. Both her parents are from Jamaica but Alicia was born in the UK. At about the time Alicia's illness began, her father died, and her mother Marianne believes that Alicia is possessed by her father's spirit. She took Alicia to spiritual healers in Jamaica 2 years after she became ill to have the spirit exorcised.

Alicia's first admission was to a child psychiatry unit, following which Marianne took legal action to get her discharged. Alicia is overweight and has insulin-dependent diabetes and learning difficulties. During one psychotic episode she ran into the road and was injured by a car, which has left her with limited mobility.

As Alicia has difficulty managing her diabetes, a nurse comes daily to administer her insulin injection. Marianne has impaired vision and back trouble, and to assist her a home help was arranged, but she stopped the service after receiving a bill for it.

Marianne has two older children, Nelson who lives close by and attends a college of higher education, and Claire who lives with the family but who is studying maths at another college and spends little time at home. Marianne has at times locked Alicia in the house when she has gone out because she feels she cannot trust her to stay in on her own. Alicia eats indiscriminately and will take Claire's food. She spends a lot of time in bed.

### *Presenting problems*

Mother can be quite antagonistic to the psychiatric services and has to be approached cautiously over every issue. She seems to be incapable of keeping Alicia to the recommended diet. She has blocked attempts to get Alicia to attend a day centre in the past on the grounds that she would not get the attention and understanding she needs. How can Alicia's

physical health be safeguarded? How can she be encouraged to be more active and do more for herself?

### *Formulation*

Alicia has three different sets of health problems: schizophrenia, learning difficulty and diabetes. Her learning difficulty has been present since birth and her other two conditions since childhood. It is not surprising, therefore, that her mother has developed overinvolved and overprotective attitudes. These are shown by Marianne removing Alicia from the child psychiatry unit, not wanting her to attend a day centre and locking her in the house on her own. She is antagonistic to the psychiatric services, an attitude commonly seen among overinvolved carers, who fear the professionals will displace them from their valued role. Consequently they denigrate the services offered and question the competence of the professional carers. The therapist felt she had to be very cautious in the suggestions she proposed for fear of antagonising Marianne.

There is an additional complication arising from Marianne's belief that her daughter is, or was, possessed by her dead father's spirit. This could lead her to reject biomedical explanations of Alicia's mental problems. This belief is consonant with Marianne's cultural upbringing in Jamaica (see Family 1). It is vital to avoid conflict with carers over explanations for a psychiatric illness in a family member. The therapist can state that there are many different ways of explaining these illnesses and that it is most helpful for the patient when each party respects the preferred explanation of the other.

The therapist has to be extremely careful to avoid the carer feeling that they are being criticised and displaced from their role. It is essential to recognise that overinvolved carers are doing what they believe to be best for the patient, and are devoting a huge amount of time and energy to this task, which has often become the centre of their lives. The first step in defusing the carer's suspicion of professional intervention is to congratulate them on the care they are giving their relative and express awareness of how much time and energy it takes. Once the therapist has reassured the carer, they can proceed to discuss how the carer can help their relative to become more independent. It is important not to exclude the carer from this endeavour or they will sabotage it. In this instance Marianne could be asked to accompany Alicia to the day centre for a trial visit and to help her choose a suitable activity that she might enjoy.

It was discovered a long time ago that carers respond more normally when asked about their healthy children than when the enquiry is about the child with mental illness (Sharan, 1966). Consequently Marianne should be congratulated on bringing up two such successful people as Nelson and Claire, latterly without the help of a husband. The children should be invited to at least one family meeting for a number of reasons.

Healthy children, particularly those who have successfully achieved independence, are often able to be objective about the family situation and to make perceptive observations in direct language. They may be induced to share some of the caring tasks, thus reducing the burden on the primary carer. They may also be able to help the patient socialise with an age-appropriate peer group.

Alicia's triple health problems require close coordination between the different services involved. It is often difficult to achieve a good working relationship between services for adult mental illness and for learning difficulties. Commonly each service would like to shift the whole responsibility for the patient to the other. It becomes even more complicated to manage when a service for physical illness is also involved, as in Alicia's case. It is most helpful to convene a joint meeting between representatives of all the relevant services with the aim of agreeing on a rational management strategy. Alicia's overeating may stem from her learning difficulty, or her schizophrenia, or may be an independent eating disorder. Whatever its origin it is inimical to control of her diabetes, and illustrates the necessity for communication and coordination between the three services. It is advisable that Marianne be invited to attend this meeting as an active participant, since if she feels excluded from the decisions, she is likely to sabotage whatever plan is agreed upon and to set one service against the other.

### *Supervisor's suggestions*

1. Meet with Marianne and Alicia and congratulate mother on the fulfilling of her caring role. Suggest that mother takes Alicia to the day centre and helps her choose an appropriate activity.
2. Invite the healthy brother and sister to a family meeting and ask them each to suggest one thing they could do to help Alicia.
3. Organise a meeting of all the professionals involved in Alicia's care and include Marianne.

### *Follow-up*

#### **1 month**

The therapist saw mother and Alicia together. Mother talked for Alicia all the time and did not give her the opportunity to answer any questions directed to her. The therapist made it clear that she valued mother's opinion, but stated that she would like to hear from Alicia what she would like to do. Alicia responded by saying she was bored in the house and would like someone of her own age to talk to. She was interested in attending a day centre, but then mother intervened and asserted that the people at the centre were all worse than Alicia and that it would depress her. The therapist agreed that that was a

possibility but added that it was worth trying unless mother could suggest another place where Alicia could meet young people. She asked mother if she would take Alicia along to the centre and help her to choose an activity she could benefit from. Mother raised a number of objections and would not commit herself to the plan. The therapist asked her to think it over and said they would discuss it again on her next visit.

## **2 months**

The therapist tried to arrange for the other two children to join them for the next meeting. Nelson made the excuse that he was too busy, but Claire agreed to attend. At the meeting, Claire was openly critical of mother's inability to control Alicia's overeating and said mother was endangering Alicia's health. The therapist intervened to point out that mother was herself incapacitated and needed help with Alicia's care. She asked Claire to suggest one thing she could do to help mother with Alicia. Claire then asked her mother how she could help and Marianne said she should lock up her own food so that Alicia could not get access to it. Claire agreed to this.

The therapist then raised the issue of the day centre. Claire was strongly in favour of this and pressurised Marianne to try it out at least once. She offered to take time off college to accompany them to the centre. After some argument all three agreed to go together and a specific date was fixed.

## **3 months**

The therapist reported that it had proved very difficult to get all the agencies to attend a meeting. Finally a meeting was held with Marianne, the nurse who gives Alicia insulin injections, the psychiatrist responsible for Alicia's care and a member of staff at the day centre. Nobody from the learning difficulties service attended. Discussion focused on control of Alicia's eating problem and her activities at the day centre. It was agreed that the day centre staff would teach Alicia to plan and prepare simple meals within her diet. Marianne was sceptical about her daughter's ability to master even the simplest cooking skills but was prepared to go along with this plan.

## *Commentary*

By being congratulatory, patient and resourceful, the therapist was able to overcome Marianne's antagonism to psychiatric services and personnel. Claire, the healthy daughter, who was direct in her comments to her mother and supportive of the therapist's aims, helped in this task. It is very likely that Marianne has underestimated Alicia's abilities and that she will be able to benefit from the training in food preparation at the day

centre. The hope is that giving her more control over the choice of food and its preparation will engender in her a better understanding of the limits of her diet.

The attempt to bring together representatives of all the services required by Alicia was only partially successful. This is a common experience and reflects the lack of coordination of specialised services. Nevertheless the meeting was useful in reaching agreement between the professionals and Marianne on a plan for Alicia, which would be administered by the day centre staff. The opportunity for professionals from a variety of services to meet and discuss a client together establishes a basis for ongoing communication, a necessity for someone like Alicia with both psychiatric and physical problems.

If Alicia settles into the day centre and spends more time away from her mother, it will be necessary to help Marianne to find an activity to fill the gap that opens up in her life. Voluntary work is a possibility, but may be ruled out by Marianne's own physical disabilities. An alternative would be for Marianne to attend a day centre for the elderly, which would enable her to expand her social network.

## **Family 5. Martin Edwards**

### *History*

Martin is aged 39 and has suffered from paranoid schizophrenia since the age of 20. He is the youngest of three children, the older two being from his mother's previous marriage. His biological father died 5 years ago. His mother Jacqueline is aged 70 but is very active. She goes out a lot, plays bridge with a group of friends weekly and travels abroad. Her first marriage ended in divorce and her second marriage in a separation. Martin lived with his father for a while and was very upset by his death. Jacqueline felt that Martin's father turned him against her.

Martin lives alone in a council flat not far from his mother, who does everything for him. She does all his shopping and collects his medication when he asks her. She is so worried about him that she says if she knew she was going to die she would take him with her. On the other hand, when she goes abroad Martin worries about her.

Martin has a girlfriend, Patricia, whom he met when she was on the same psychiatric ward 2 years previously. She is addicted to cocaine and spends most of his money on her habit. She only visits him on his benefits day, which is when she commandeers his money. However, she makes an effort to get him to go out. He is hard of hearing but doesn't use a hearing aid. He gets very paranoid and hears voices, and also misinterprets what he hears from television and people in the street.

This is the main reason why he avoids going out. Patricia is his only friend, although he can get paranoid about her too.

Martin's stepsiblings are Tony, a successful businessman who would like to help Martin, and Susan, who is married with two children.

### *Presenting problems*

How can Martin be persuaded to use a hearing aid? Is it possible to work with his girlfriend, or should she not be involved in the work with him since she has psychiatric problems of her own? What can be done to reduce his mother's overinvolvement?

### *Formulation*

There is an association between deafness and paranoia, so that it is quite likely that Martin's physical disability contributes to his paranoid beliefs that people in the street are talking about him. I once looked after an elderly man who was deaf and suffered from auditory hallucinations. On being asked when he heard the voices, he replied that they only came on at night when he went to bed. I asked him what he did with his hearing aid at night and he told me he turned it off. I advised him to keep it on, and at his next visit he reported that the voices had stopped. Research on sensory deprivation has shown that those without mental illness can develop hallucinations when the input of meaningful information is reduced to a minimum (Leff, 1968). Therefore it would be an important aim to induce Martin to be fitted with a hearing aid and to wear it regularly.

Like many people with schizophrenia, Martin's social network is very sparse. One of the reasons in his case is his paranoia, which is even directed against people he knows well like Patricia. However, given the fact that Patricia undoubtedly exploits him, his paranoid attitude to her has a basis in reality. His mother is extremely overinvolved as shown by the number of things she does for him and her statement that if she died she would want to take him with her, as though he could not survive without her. She would probably benefit from attending a carers' group.

The other people in his network are his two stepsiblings, one of whom, Tony, has expressed willingness to help him. An attempt should certainly be made to recruit him as an ally in the process of improving Martin's quality of life. He is likely to prove easier to work with than either Martin's mother or his girlfriend. His stepsister is another possible ally but may be too busy with her children to offer much. However, her children, Martin's nephew and niece, have the potential to provide him with a valued role as an uncle. People with schizophrenia generally find children less threatening than adults.

*Supervisor's suggestions*

1. Advise Jacqueline to join a carers' group.
2. Explain to Martin that a hearing aid could help to reduce the frequency with which he hears voices.
3. Invite Tony and Susan to a family meeting with the aim of recruiting Tony to help persuade Martin to use a hearing aid.
4. See Martin together with Patricia and stress the fact that they both have a disability that could be helped. Suggest that Martin encourages Patricia to enter a detoxification programme and that she encourages him to acquire a hearing aid and to use it regularly.

*Follow-up***2 months**

The therapist encouraged Jacqueline to join a carers' group, which she did and benefited from it. The other group members advised her to withdraw a bit from helping Martin, and she is trying to do this. Martin has been shopping for basic foodstuffs on his own and is generally becoming more active. The therapist is encouraging Patricia to press him to get a hearing aid.

**3 months**

Martin's siblings attended a family meeting and were very supportive of him. Tony suggested that he could arrange for Martin to have a hearing test and could drive him to the clinic. After some hesitation, Martin agreed to this plan. Susan asked him if he would like to come to her home for tea one weekend, and he accepted.

*Commentary*

The therapist was faced with the dual difficulty of trying to work with an overinvolved mother and a girlfriend who took advantage of Martin financially in order to fund her substance misuse. In these circumstances it is always worth assessing whether there are healthy siblings available who could be recruited to aid the therapist in his or her task. In this case Martin's stepsiblings were willing to take action to help him and both made useful offers that Martin agreed to take up. In the absence of further follow-up it is not certain that he will keep to his agreement, but at least the meeting achieved the aim of activating part of Martin's very small social network.

The problems of modifying intensely overinvolved relationships when the carer has no other source of emotional satisfaction are formidable. Engagement with a carers' group can be very helpful in a number of ways. The group becomes part of the carer's social network

and combats the sense of isolation. It also helps to provide an outlet for distressing emotions and the group members can be much more direct in instructing the carer what to do than the therapist dares to be. Jacqueline has another resource that she appears not to be using, namely her grandchildren. They could provide her with another focus for her need to care, thus taking some of the pressure off Martin. A future aim for the therapist would therefore be to encourage Jacqueline to spend more time with the grandchildren.

It is easy to be very negative about Patricia because of her blatant exploitation of Martin, but she is an important member of Martin's sparse network and needs to be included in the therapeutic work. After all she remains with him even though he can be paranoid about her. Emphasising that they both have a disability puts them on an equal footing. The aim of suggesting that they can help each other overcome their disability is to bring out their capacity for caring and to put a positive connotation on their mutual dependency. There is no information available from further follow-up on the success of this approach.

## **Family 6. Margaret Brown**

### *History*

Margaret is aged 44 and has a mild learning disability. She developed schizophrenia at the age of 19. She struggled at school but can read and write a little. She describes herself as 'a dunce' and reported that she couldn't keep a job, explaining that 'I wasn't very good'. Her sister Janice did well academically, married young and has had four children.

At age 32 Margaret married a man who also had a mild learning disability. There were a lot of difficulties in the marriage, affecting communication and their sex life. After a year they received help from a psychiatric clinic. This continued for a year and then they began to sleep separately. She stopped doing any housework and he started shouting at her. Her parents then took her back into their home, where she has lived for the past 9 years. She has no contact with her husband now.

She has been attending a day centre twice a week and also a yoga class for the general public. At the centre she is in an art group and her paintings are very colourful and bold. The teacher considers them to be of a high standard. She also attends a women's group at the centre and is able to express her feelings. Recently she began missing days and her father went to the centre and reported that she was spending more time at home. Margaret saw the psychiatrist and conveyed her worries about how she would cope when her parents die. They are both in their

eighties and have expressed concern about who would care for their daughter after their death.

She was visited at home by a staff member who found that her parents do everything for her. Margaret complained that her life is empty.

### *Presenting problems*

How can Margaret be helped to feel more confident of her abilities and to achieve more independence? She has a good potential to express herself but has no social life outside of the centre and spends all her time with her elderly parents.

### *Formulation*

Margaret's parents have overreacted to her mild learning disability by overprotecting her. As a result, she has very low self-esteem and responds passively to their taking over her activities. Her schizophrenia is well controlled with medication and she has not experienced any psychotic symptoms for some years. Her dependence on her parents naturally generates anxiety about how she will cope without them.

On the other hand, she managed to leave home to get married and kept a difficult relationship with her husband going for several years. During that time she coped with the housework. The break-up of her relationship must have been a severe blow to her confidence and led her into her current position of helplessness. However, her painting reveals a lively and colourful aspect of herself that could be encouraged to emerge more strongly.

There are complex emotional issues between a person with schizophrenia and their healthy siblings. Margaret's sister was successful academically, has a stable marriage and has had four children, achievements that Margaret has failed to attain. She must feel envious of her sister and believe that she is a disappointment to her parents. These feelings may be causing her to distance herself from Janice, who could otherwise be a valuable source of support to her. However, Janice may be anxious that after their parents' death the full responsibility of Margaret's care will fall on her, adding to the task of bringing up four children.

### *Supervisor's suggestions*

1. Explore Margaret's feelings of loss and lack of fulfilment regarding her broken marriage and childless state compared with her sister. Stress her creativity as shown in her paintings.

2. Congratulate her parents on their care. Allow them to express their anxieties about Margaret's future after their deaths, and discuss how they can help her to develop the necessary self-care skills now.

## *Follow-up*

### **1 month**

The therapist had seen Margaret twice, once with both parents and then with mother only. The parents blossomed on being congratulated on their care of Margaret. At the first visit Margaret was asked what she could do for her parents to thank them for their care of her. She agreed to make them a cup of tea. At the second visit 2 weeks later Margaret offered the therapist a cup of tea. Her mother reported that she had also been doing the vacuuming and washing up. The therapist negotiated that Margaret should make her own bed. The therapist noted that mother looked very sad and asked her about this. She related that her husband goes out to the cinema alone and leaves her to do the housework. The therapist is looking for an art class for Margaret.

#### *Supervisor's suggestions*

1. To see the parents without Margaret and give them the task of going out together and enjoying themselves.
2. Margaret needs to be engaged in a task while they are out.

### **2 months**

The therapist asked if father would come to the next session. Both women said 'he gets in the way'. She negotiated another task for Margaret - ironing. Margaret then wanted to bake a cake. She bought all the ingredients and successfully made a cake. However, the parents were lukewarm about it. It is evident that they had not really appreciated the effort Margaret had made and that the family members had not yet recognised the importance of giving positive feedback to each other.

Margaret said that father needed a new suit. As a result the parents decided to go on a shopping expedition together. Father said that Margaret would want to come with them but she declined firmly. The therapist negotiated for Margaret to make ham sandwiches for them for their tea in their absence. She reported that the parents often talked about Margaret in the third person in her presence and that they were sometimes critical of her efforts.

#### *Supervisor's suggestions*

1. Concentrate on communication between the family members. Encourage direct communication at all times and reframe criticism as caring.
2. Assist parents to develop realistic expectations for Margaret.

3. Link them to the extended family, namely Janice, her husband and their children.

### 3 months

The shopping trip went very well. Margaret made the ham sandwiches in 10 min and then got bored waiting for her parents' return. She again doubts her abilities.

Mother is very sad that she is alienated from her other daughter, Janice. She is married to an Asian and they are of different religions. The parents are only in touch with one of their grandchildren, a girl who has a daughter of her own.

Father has spent 2 days in hospital because of a heart condition. The parents have made a will and discussed it with Margaret. They have left her the house. At the day centre, Margaret has been talking about death and the possibility of predicting it. She now goes somewhere for organised activities four times a week.

#### *Supervisor's suggestions*

1. Margaret needs more practice of her skills to increase her sense of mastery.
2. The issue of the parents' mortality is now out in the open and can be discussed.
3. Negotiate more outings for the parents.
4. Encourage the family to strengthen the link with the granddaughter.

### 4 months

Father was in hospital for 10 days to monitor his anticoagulant. Margaret was more active in father's absence but stopped when he returned. He said things like 'She's useless'. On being asked, Margaret said he made her feel that she wasn't there. In his absence Margaret began going to the shop to get the newspaper and has continued with this task. Mother and father continue to go out together and leave Margaret for up to 4 h. The therapist took her to an art class at a local adult education centre as Margaret felt she couldn't manage the journey on her own.

Margaret is overweight and wears unusual clothes – a baseball cap and dresses suitable for an elderly woman. Mother chooses the dresses for her.

The therapist is trying to find a support worker for Margaret. She would like to go to the seaside for the day, as she used to with her parents, but father is unable to travel there and mother won't leave him. Margaret has taken a 3-week break from the day centre.

#### *Supervisor's suggestions*

1. Arrange sessions with Margaret alone in addition to the family sessions. Raise the issues of her diet and clothing. Try to get her to choose from magazines what clothes she likes.

2. Explore the possibility of her attempting to travel by bus.
3. Reframe hostile comments from father and encourage him to thank her for her contributions to the household.
4. Restate the therapist's role and check the family members' current goals.

### **5 months**

Meeting held with the family for review. Father had not attended the previous meeting. Margaret said she felt more confident. She had decided to go on a diet and parents agreed to follow the same diet. Margaret is keen to meet with Janice and her children, and suggested that she write to Angela, her niece. The therapist helped her to write the letter. In fact, she didn't need much help even though mother said she writes rubbish.

#### *Supervisor's suggestion*

Meet with the parents on their own for them to express grief and mourning for the loss of their other daughter and their hopes and expectations for Margaret.

### **9 months**

Margaret has moved into a group home. The other residents also have mental health problems but she is the only woman. She has a bedroom of her own but worries about using the bathroom shared with the male residents. No staff are on duty at night. She spends the weekdays in the hostel and weekends with her parents.

In response to her letter, her sister and niece came to visit over the summer and Margaret felt very proud about achieving this rapprochement.

Her antipsychotic medication has been reduced to once per day and she has perked up a lot. Her anxieties about using public transport are partly due to the fact that she gets laughed at because of her odd clothing.

#### *Supervisor's suggestion*

The therapist to see the parents on their own to discuss their feelings of loss and to explore ways of filling the gap left by Margaret's move.

### **10 months**

A meeting was held with the parents. They are feeling lost and decided to organise activities for themselves. They were enthusiastic about the therapist's suggestion of going to an Age Concern centre.

Margaret's sister and husband converted to Jehovah's Witnesses, which has deepened the schism in the family.

Margaret has found another bathroom in the hostel that is little used and feels more comfortable with that. She is prompted by her parents to

wash and change underwear. She now attends another day centre three times per week and successfully manages two buses to travel there.

The therapist is continuing to meet with Margaret and her parents every 3 weeks.

## 12 months

Margaret is doing well in the hostel. A support worker is taking her out shopping to buy her own clothes for the first time. She went to the hairdresser for the first time and is painting her nails yellow and orange. She now uses public transport by herself without any problem.

Family meetings now occur monthly. The parents continue to feel emptiness. Father went to the Age Concern day centre but considered it wasn't suitable for him 'or for mother'. However, the therapist asked mother if she would like to go and she said yes.

## 21 months

The support worker sees Margaret weekly. She goes out with her shopping and to museums. Margaret attends a sewing group and an art group. She had an exhibition of her paintings and drawings but her parents refused to attend.

The hostel staff do everything for her. It is a struggle to get her to do things for herself. The culture in the hostel appears to be that staff do everything for the residents.

Margaret still stays with her parents every weekend. Mother is now almost blind.

### *Supervisor's suggestions*

1. Persuade father to encourage Margaret to wash up after one meal during her visits and to praise her for it.
2. Meet with the hostel staff about encouraging autonomy.
3. Remind Margaret to maintain contact with her niece.

## *Commentary*

These parents had responded to their daughter's learning difficulties and subsequent schizophrenia by abandoning all expectations for her. As a result they made every decision for her and found it impossible to recognise her potential for improvement. Father in particular was very rigid in his attitudes to women, leaving his wife to do the housework while he went to the cinema. Presumably it was his rigidity that created the rift with his married daughter. Sadly the parents failed to visit Margaret's exhibition of her art, passing up the opportunity to admire this demonstration of her success.

Margaret's low self-esteem derived partly from the contrast with her successful sister and partly from the persistent critical attitudes of her

parents. Their overinvolvement was gradually reduced by gaining their trust in the first place and then by recruiting them to help Margaret develop self-care skills. This process was made possible by bringing their anxieties about their daughter's care after their deaths into the open. Sometimes the only way to reduce the overinvolvement of older parents is to face them with their mortality. Inexperienced therapists may feel inhibited about talking to parents about their death, but awareness of the problem is inevitably present even when unspoken. The necessary practicalities can only be planned for when the issue is discussed openly, and the therapist may have to take the initiative. Margaret's parents were only able to make their wills and secure Margaret's financial future when their deaths could be spoken about.

The rift in this family between the parents and their older daughter is encountered relatively rarely in this type of work. A therapist may feel that it is outside their remit to tackle this problem but it is bound to have an emotional impact on the person with schizophrenia. In this family the parents concentrated all their emotional needs on Margaret, instead of including Janice, her husband and their children. Healing the rift took some of the emotional pressure off Margaret. In fact, Margaret herself initiated the action that re-established communication with the alienated part of the family.

It is noteworthy that the therapist had never worked with a family previously. It is a tribute to her empathy, warmth and persistence that she was able to help Margaret to leave her parental home and achieve a degree of independence. Unfortunately the staff in the hostel to which she moved were also overprotective, as shown by their performing tasks which the residents should have been encouraged to manage themselves. A number of studies have found critical attitudes towards the residents to be quite common in staff in hostels (e.g. Ball *et al*, 1992). Overinvolvement is rarer but certainly was in evidence in Margaret's hostel. An educational programme for staff, based on schizophrenia family work, has been developed and has been shown to improve their attitudes towards residents and to increase their coping skills (Willetts & Leff, 1997, 2003).

It is fortunate that the therapist was able to work with this family over an extensive period. This is of particular value when family members exhibit overinvolvement, since this set of attitudes takes considerably longer to modify than does criticism.

## **Family 7. Costas Papageorgiou**

### *History*

Costas is aged 43 and lives with his mother Maria. The family emigrated from Cyprus to the UK in the 1970s. The father died 5 years previously. Another brother Regis is married and lives in London. Mother is

incapacitated by angina and arthritis in her knees. She cannot get to the shops and relies on Costas to go shopping and run errands.

Costas has a mild learning disability and went to a special school. As a teenager he identified with great singers and dancers and was grandiose. He developed schizophrenia at the age of 20 but was not seen by a doctor. Instead he spent 10 years in his bedroom being cared for by his family. Finally the family sought help from services. He was admitted to a psychiatric hospital with grandiose delusions of identity and spent 5 years as an in-patient. He was then transferred to a day hospital, which he attended for 2 years. Following this he was moved from the parental home to a hostel. However, after a year he moved back with his parents.

### *Presenting problems*

Costas believes he is either very attractive or very ugly and spends a lot of time staring into a mirror. He asks for reassurance and mother reacts by exaggerating his attractiveness. He is socially quite isolated, though he does go to the local shops. Mother does all the cooking.

Costas finds it difficult to accept mother's increasing disability. He gets angry with her and can be quite threatening. His self-care is quite poor and his teeth are decaying. He stays up late to watch television and gets fixated on particular women who appear on programmes.

He is maintained on a depot antipsychotic, received every 2 weeks, plus chlorpromazine at night.

### *Formulation*

Women live longer than men, so it is not uncommon to find a middle-aged person with schizophrenia being cared for by an elderly mother, as in the Papageorgiou family. The mother's life often centres on the care of her sick offspring to the exclusion of all else and the ill person develops an extreme dependency on their mother. Consequently it is very difficult to separate the couple. In this family the dependency was heightened by Costas's learning difficulty and the fact that the family kept his illness hidden for 10 years. Evidence is accumulating that a long duration of untreated psychosis results in organic changes in the brain (Lappin *et al*, 2003), this being one of the arguments for the early detection and treatment of psychosis. Another reason for early intervention is that it prevents carers' emotional responses to the patient from becoming fixed and difficult to modify. Considering the length of time Maria has been caring for Costas, her limited life expectancy and her dependence on her son to shop and run errands, it is unreasonable to consider attempting to separate them at this stage.

Costas's dependence on a caring environment was perpetuated by his spending 5 years in a psychiatric hospital, exposed to all the problems of institutionalisation. It is hardly surprising that he did not manage to

remain in the hostel but returned home to his family. Patients cared for by a single elderly relative invariably harbour anxieties about the relative's health and fears of what will happen to them when the relative dies, even if these are unvoiced. Costas deals with these fears by denying his mother's increasing disability and becoming angry about her incapacity, as though it were under her control.

He needs to be helped to express these fears in a direct way and to prepare himself for a future without his mother's care. He should be congratulated on the tasks he does do for her and encouraged to gradually extend them.

However, he is quite handicapped by his persistent delusional concerns with his appearance. These have not responded to his regime of medication and he needs to see a psychologist for exploration of a cognitive approach. This may be hampered by his learning difficulty.

His healthy brother Regis is the only other close family member and might be able to help Costas by taking him out occasionally.

### *Supervisor's suggestions*

1. See Costas individually for an exploration of his fears about mother's ill health and eventual death.
2. Meet with Costas and Maria together to discuss additional ways in which he could help her. It is a useful approach to remind Costas how much his mother has done for him over the years and ask him to think of ways in which he could thank her for her care.
3. Arrange for Costas to see a psychologist for assessment of his suitability for cognitive therapy.
4. Attempt to arrange a family meeting including Regis.

### *Follow-up*

#### **6 months**

Costas settled down for a few months after the family was discussed. Then Regis's marriage broke up and he moved back into the family home 2 months ago. Six weeks ago mother phoned to report that Costas was trying to kill Regis because he believed that Regis was maltreating their mother. Costas was punching and kicking Regis's bedroom door. Regis called the police. After they went Costas became angry about their having been called and got more aggressive, so they were called again. More recently Costas hit his mother with a mug. He is becoming more paranoid. He is also worried about having AIDS although he has never had a sexual relationship, but masturbates excessively.

Regis is keen to learn more about schizophrenia and Costas is happy for Regis and mother to know more about his illness. Costas admires Regis's ability to get on with people.

*Supervisor's suggestions*

1. Educate the family about schizophrenia. Despite the prolonged period Costas spent in hospital, it is possible that Maria was never given education in any form.
2. Meet with the two brothers to discuss their relationship and ways in which Regis could help Costas.
3. See Costas alone about his sexual difficulties. Refer him to a psychologist to work with him on his delusions.

**13 months**

Since the last discussion he has been admitted to hospital twice. The dose of his depot was increased and since then he has been less aroused. When he settled on the ward he enjoyed being able to talk to people.

A psychologist has engaged well with Costas. They have worked on his belief that he is ugly and that people in the street call him a monster. During therapy there was a re-emergence of paranoid ideas that mother and Regis were conspiring against him.

He has a strong interest in music and sings reasonably well.

*Supervisor's suggestions*

1. Teach mother and Regis how to defuse tense situations and how to cope with Costas's expression of delusions.
2. Explore the possibility of appointing a befriender with an interest in music. Costas is very isolated but on the ward he proved capable of socialising with the other patients. A befriender with a sympathetic approach might be able to form a good relationship with him and take him to musical events that he would enjoy.

**14 months**

Maria is very happy to have help with Costas's aggression. Costas agreed that his mother could be seen by the therapist to give her help. There is no progress in finding a befriender. Unfortunately there is a limited supply of volunteer bendifenders and they have to be chosen carefully to match a particular individual's needs.

A meeting was held with Costas and Regis. Costas expressed his worry that his brother would take his mother's attention away from him and that they would both try to send him away to a hostel again. Regis was able to reassure him that he was only staying with them until he found a place of his own that he could afford. He also stated that both Maria and he wanted Costas to live at home as long as Maria could care for him. Regis asked Costas if he would like to go with him to a musical evening at a local Greek Cypriot centre. After some hesitation because of the worry that people would stare at him, Costas agreed.

## Commentary

It is very unusual these days to find a person with schizophrenia who has been kept at home by their family without treatment for many years. This kind of situation is produced by ignorance of the nature of serious mental illness, pessimism about the possibility of treatment and a strong awareness of stigma. People from minority ethnic groups most often express the latter (Wolff *et al*, 1996). Successful reduction in the period of untreated psychosis has been achieved by early intervention programmes, which include education of general practitioners and the introduction of mental health education classes into secondary schools (Larsen *et al*, 2001).

The people who are most at risk from violence by a person with schizophrenia are family members (Taylor & Gunn, 1999). Yet professionals rarely, if ever, advise them about the warning signs (persistent stare, gritted teeth, clenched fists) or about strategies to defuse tension (time out, carer leaves room, distraction by a task that takes the patient out of the home, e.g. 'Would you please take the dog out for a walk.').

Carers often ask professionals what to do when their relative speaks to voices or expresses delusions. For decades they were given the useless advice to ignore them. Cognitive-behavioural therapy, which has been successful in helping many people with persistent delusions or hallucinations, has not been utilised to advise relatives how to cope with the patient's psychotic symptoms. Maria's attempts to reassure her son when he complains that he is ugly have not benefited him. She needs to be instructed in responses that have been shown to work.

Costas's anger at and suspicion of his younger brother's return home is understandable in view of his lack of success in life compared with Regis. It can be very helpful to hold a joint meeting between the siblings to discuss these emotional issues. In this case Costas's paranoia was defused for the time being and the better feeling between the brothers led to a helpful offer from Regis to take Costas to a musical evening. On Maria's death, Regis will be the only surviving relative of Costas in the UK. If he does not succeed in making any friends by then, he will be reliant on his brother for social contact. Therefore the therapist needs to focus on this relationship, attempting to defuse the negative emotions involved and to resuscitate the warmth that existed before Costas fell ill.