Retreat Lecture 2014
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'Friends, meet together and know one another in that which is eternal'
(QF&P 2.35 from Epistle 149, 1657)

When I read this quotation from Georg Fox recently I thought it was wonderful. It seemed to say to me that if we meet together we will know one another. When I read it again the message was different. We were given two things to do; to meet together and to know one another. This felt like a challenge rather than an assurance.

The quotation had caught my attention in preparation for this lecture because it speaks of developing **relationships** and relationships are key to my thinking about mental health issues, particularly mental health issues in communities.

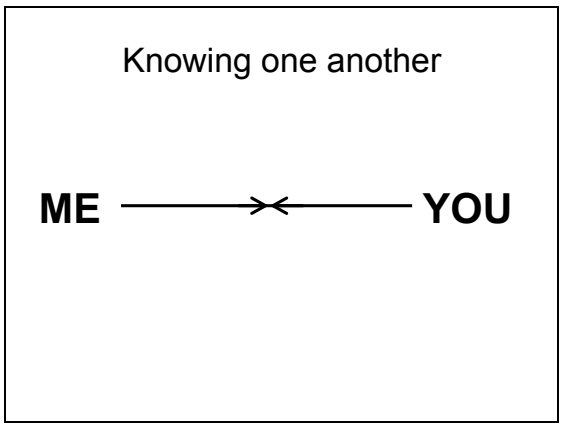
This lecture will fall into three parts. Initially I shall explore some ways in which mental health issues show in and affect relationships. I shall then say something about some aspects of the work of The Retreat before looking at positive aspects of relationships which can be emphasised in communities such as Quaker Meetings especially when the Meeting is living with mental health issues.

1. '<u>Know one another</u>'

Back to the quotation I started with. 'Know one another' – to know and to be known. I am struck by the first question frequently asked when someone talks of caring for a person close to them with advancing dementia problems 'Do they still know you?' or the reassurance given 'but they still know me'. In this context we are talking of a very limited knowing which may be saying a name, a particular smile or just responding in a familiar way to a particular action. Each is really important in the context of a long relationship, giving that relationship continuity.

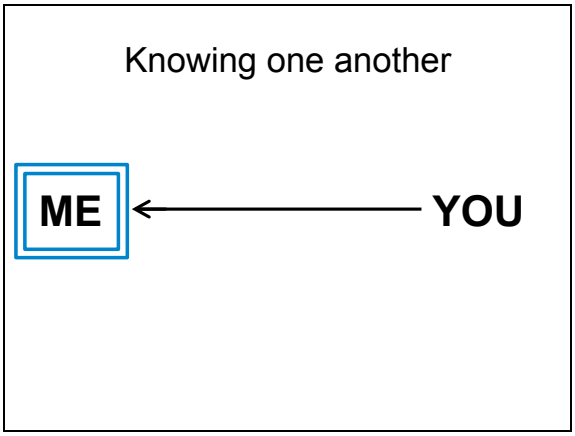
In most situations we expect more than that in being known. We expect another to have some understanding of our feelings, needs and ideas and to show that they recognise these. As we seek to know one another, our role in a community is to offer the same to the other and to build what we hope and expect will be a reciprocal relationship. I note here the word 'expect'. As I shall explain, with mental health issues relationships may not develop as we 'expect' and this can cause anxiety, uncertainty and possibly an avoidance, because we cannot make sense of the situation and are not sure what to do.

I often draw a diagram to represent this type of reciprocal relationship:



The important bit in this is the line between. I usually put arrows on this - I pay attention to you, you pay attention to me, I understand you, you have some understanding of my position and needs. We could be seen as coming together somewhere in the middle, adapting to each other, meeting at varying points at different times as the needs of each vary.

It became clear to me that with dementia problems the pattern tends to change. (But people with dementia problems are diverse and the pattern I illustrate here though common is not shown by everyone.):



The Me with dementia problems will tend to become more and more locked into their own experience, because of their cognitive disability. This disability limits how much 'I' can pay attention to and understand. It will limit how much 'I' can understand and pay attention to the position of another person 'you'. 'I' may well have some sense of how you are feeling, as our research showed, but then not understand this , its origins or what 'I' can do to support 'You'.

There is still a relationship but 'you' have to do all the adapting. 'I' am trapped in my own reality and cannot move out of this to recognise yours. The phrase 'in a different reality' is often used in this context.

The important thing for 'me' is that you recognise my reality, how I am experiencing the world and adapt to it. 'I' may be very content in my reality, not distressed by it as I cannot step outside and look at the overall situation.

A positive description of someone with dementia problems:

The old age of William Penn:
His memory was almost quite lost, and the use of his understanding suspended; so that he was not so conversible as formerly; and yet as near the Truth, in the love of it as before….. His mind was in an innocent state, as appeared in by his very loving deportment to all that came near him: and that he still had a good sense of Truth was plain by some very clear sentences he spoke in the Life and Power of Truth……; where in we were greatly comforted…..(QF&P 21.62: Thomas Story, 1714)

It is important that those around 'me' are positive, responding to my feelings and needs, not undermining me by questioning or challenging. Trying to get 'me' to change my position will be confusing for 'me'. Those outside may not be able to recognise the 'facts' of 'my' position but they can respond to 'my' feelings and needs.

The 'me' with dementia is trapped in their reality. There is a loss of the reciprocity, the give and take which we expect in a relationship.
This is a lonely position for 'you' the supporter. You have lost the support and understanding which has made this a reciprocal relationship. Making all the adaptations is hard work. 'You' have to see the relationship in a new way and try to become reconciled to a new situation. 'My' reality may be too far from 'yours' for you to understand it but if 'you' respond to 'my' feelings and needs you will be doing the best for me.

A similar loss of reciprocity can happen when people become trapped in their own perception of reality for other reasons. This may be because of overwhelming emotions, overwhelming practical demands or dominating thought patterns. Here is one of the dangers of 'great busyness'. But it is also one of the isolating aspects of intense emotion or obsessive or racing thoughts. My images here are for some of a deep pit or for others a spinning wheel.

There are also those who live with what I have sometimes regarded as an emotional disability, similar to but different from the cognitive disability of dementia I was talking about earlier. These are people who habitually see reality through the lens of their own current varying emotional needs and cannot reflect on this. Their views, often expressed strongly, change as their needs change leaving those around them with a sense of uncertainty, upset and chaos. My image here is of a whirlpool.

To support people in these situations one can throw a line but one does not jump into the pit, onto the wheel or into the whirlpool. As a would-be supporter one has to keep ones feet on firm ground, firm in ones own reality, faith and experience. Perhaps giving a glimpse of the existence of an 'ocean of light' to one who feels they are in an 'ocean of dark

Drawing this section to a close:
As I have reflected on the process of reciprocal relationships 'knowing one another', I recognise that each of us lives with our own view of reality which we share more closely with some than with others. We all vary in how easily we can enter into or understand the reality of another. This varies with how far their 'reality' is from ours

but also with how we are feeling and particularly how much pressure, emotional, in thinking or in action, we are under. Sometimes I can listen better than others. Sometimes I shut others out as I feel overwhelmed or busy BUT I am fortunate in that I can vary this and reflect on it myself.

In a relationship or community where there are mental health problems it can become difficult 'to know one another' in the way we expect. Relationships can become disrupted and reciprocity may not be possible. When we cannot develop a reciprocal relationship as expected all can become puzzled and disturbed. Our 'normal' ways of relating no longer work, we may no longer know what to 'expect' in response to our contact. To take some words from stories received by Quaker Life in relation to mental health: people may seem or see themselves as 'difficult', 'ungrateful', 'unaware', 'rejected'. We may avoid or feel anxious about making contact with each other.

We may find we are unable to 'know one another'.

2. The Retreat.

The Retreat, as many of you will know, was opened in 1796 by Quakers to provide care, initially for Friends and later for a wider group of people with mental health problems.

It now works with very troubled people with complex needs, people who are, in the terms of what I said before, trapped for many different reasons in many different realities. They may be people who experience dementia and other mental health issues in older age. They may be adults who show persistent self-damaging behaviour of varied sorts, people with unusual experiences of reality. They will be people experiencing very significant mental disturbance and distress.

As Chris Holman who was until recently medical director of the Retreat and who gave this lecture 3 years ago has said, 'There is the 'ideal Retreat' in many people's minds, people who know of its history and ideals, and there is the 'real Retreat' working in the everyday world today – different perceptions of 'reality'. I suspect there as many 'Retreats' as there are people thinking about it, some closer in form than others. What you will hear from me today is my view of The Retreat from the perspective of someone who visits as a Director, a Quaker and a professional not working there.

Listening to reports from each of the units at a recent day which drew the work together I picked out and was excited by three themes which seemed to run through all the work:

Build and work through relationships – to quote from the Retreat clinical model: 'We place relationships at the centre of all we do: the every day relationships between staff and patients, between patients and each other, between patients and their wider social world'.
(I think this message emphasising the centrality of relationships may be one of our messages to the wider mental health world.)

Relationships between staff and the people who use the services are not reciprocal relationships as in a community. ‘Relationships are only therapeutic if they convey a genuine respect and warmth.’ It is through entering these relationships as a person but a person with particular skills that staff know the other.

The relationships between ‘patients’ as the model says are very important, especially in the working age adult units with an emphasis on building a therapeutic community. Such a community is about knowing and being known. From Chris’s lecture 3 years ago I took the point that it can be as we are known by others that we come to know ourselves and then can choose to change.

The older people’s units are working actively to develop ‘relationship-centred’ care building on work elsewhere. Training all staff and evaluating this in a formal research project. Relationship-centred care could be seen as underpinning person-centred care which is widely emphasised in work with older people. This work has shown that all staff develop a greater confidence in their therapeutic role and become more aware of the emotional and relationship needs of those using the service. ‘I know it is OK to take time out and to think about my reaction……’

Activities to support spiritual needs at The Retreat also build relationships, based on the agreed approach to spirituality - ‘what uplifts us, what makes us whole, what connects us’. ‘One individual reported feeling connected to themselves and others “when there was time to have fun and laugh together”.’

Knowing each individual well, understanding the experience of reality of those using the services, accepting and respecting this as a point to work from. This knowing can be very precise e.g. understanding how best to encourage an older man to go out for a walk not ‘Would you like to go out for a walk?’ but rather ‘Would you like to come for a walk with me?’ – obvious when you think about it.
The story was told of how one unit enabled an older lady with complex problems to attend her granddaughters wedding. This took months of preparation, gradually building her competence and confidence so that she could join the family with dignity and self-respect. A real example of how careful work, knowing an individual well can enable them to recover some of their dignity and a sense of well-being and belonging – recovering something in a small but very personal sense.

Providing a safe space for people where they would not feel threatened or vulnerable and feel positively supported. This links for me to something one of the people using a service who had had experience of many mental health services, said to me, ‘Here I feel supported. Everywhere else I have been I have felt I was being punished.’

The units seek to provide a stable base for people and recognise that from this sense of security they may develop a greater sense of security within themselves.

Relationships underpin this sense of security but there are also boundaries. Some behaviour is not accepted within the community. The units are clear about their boundaries in terms of behaviour and the support which will be given within and by the community to individuals to help them to live within these.

There are, however, times when an individual's needs cannot be met within a particular unit or the Retreat. Living with and respecting the needs of others even with all the flexibility and support offered may be too much at for this individual at this time. Alternative care may be needed for a period. The possibility of return is likely to remain. Guidance for people in this situation on one unit says: 'recognise that this may not be the right time or place for recovery, but that this does not mean you have failed'.

This brings me to my third section which starts with providing a safe place.

3. 'Meet together'

Having looked at difficulties in 'knowing one another' in the presence of mental health issues in the first section and saying something about The Retreat in the second, I plan to draw on the work of The Retreat and other material in this section to consider what is important for 'meeting together', particularly in Meetings, even when we cannot know each other in ways we have expected.

I have found it helpful to think in terms of some of the aspects of positive relating which we use to bridge the gaps between us, which help us to 'meet together' outlined by Ruthellen Josselson. I have picked out 6 of her 8.

Holding, attachment, eye-to-eye validation, mutuality, embeddedness, tending and caring.

Holding is about providing or creating a safe place. This is central to the work of The Retreat and is something we need to consider carefully in our meetings if we are to include and support those who identify themselves as or who are seen as having mental health issues.
The first requirement is the 'genuine respect and warmth' referred to earlier. (More of that later)
In addition providing a safe place can be a challenge, where the behaviour of one may be deeply disturbing to another or others. This is where behavioural 'boundaries' are essential. There are limits to the behaviour which is accepted in this group. Also in order to feel safe we need situations to be predictable within predictable limits.

Take Meeting for Worship, for example. This needs to be a safe place for all and that involves behavioural boundaries and a level of predictability. There may be times when an individual cannot manage the boundaries of meeting for worship. There may still be ways of enabling the individual to be included. Flexibility and support can be explored by the community. Some practices I have heard of are: talking with an individual before or after meeting for worship; being flexible in the length of time for which a person joins the silence; sitting with a particular Friend who offers support; holding a special meeting for worship with its own structure and boundaries. I am sure Meetings have tried many other creative ideas which it would be good to share.
A key part of the process of maintaining boundaries whilst offering support is the genuine warmth, respect and, essentially, **clarity** with which the situation is discussed with the individual.

Attachment: somewhere to turn to, knowing someone is there.
The meeting can be a place where people know they will be supported, a place they can return to, where they will be cared about.
This can be indicated to people in simple ways through cards, e-mails or other messages, often messages which do not require or demand a reply or response are most helpful. They indicate a continuing presence and concern but make no demands though can indicate a willingness to have reciprocal contact when this is wished for. (*Local example*)
Issues do arise in meetings when too much support is asked for, particularly when this asking is focussed on a single individual. The meeting is a community and it is helpful if the support can be in some way 'owned' by the community as a whole. This may involve sharing the actual support or sustaining the individual of whom the demands are being made. (Example of a rota for telephone calls, setting boundaries as to what help one can offer etc.)

Eye-to-eye validation: 'its good to see you'
(My favourite because I know I need it.) This is when we look at someone and show we appreciate their presence or what they are saying or doing. If we are not sure as to how we will manage our relationship with someone or what might happen, it can be hard to really smile to welcome them our anxiety tends to show.
I was impressed on one of my first visits to one of the older peoples' units at The Retreat to see that everyone who came onto the unit greeted everyone who was there – so different from my experience in the NHS.
My experience is that this genuine welcome can change a relationship.
My experience.
This is an area in which I know I am constantly learning.

Mutuality: being together
In meetings we can offer people a range of ways of being together. Meeting for worship is one of these, having a discussion or doing the washing up are others. All of these opportunities are parts of our 'meeting together'. With varied ways of meeting, being together, we can offer something to people with varying needs and preferences.

Embeddedness: belonging and identity
As we 'meet together' and feel part of one whole, individuals have a base and the community grows through the recognition and acceptance of each individual even if we do not 'know' or understand each other in the commonly accepted ways. It can be very important to a person to be able to say 'I am a Quaker' or 'I go to Quaker meeting', giving an identity, a place to belong.

Being part of the Quaker community can go further giving a sense of being valued and being recognised as someone in whose life the Spirit of God is active. To quote from one of the speakers on the mental health day The Retreat organised at Friends House in March; 'Quakers had really valued me when no one else did' and from one of the responses to the day: 'you are someone with our own story, your own journey and your own calling which is linked to mine'. 'We can recognise each other, learn from each other, give to and receive from each other.' We are embedded in the same community and valued by it.

Tending and caring: giving service
Here we can offer people the opportunity to serve the community and care for others in their own way, in a way which is not too demanding of them. Without that sense of 'knowing' which we may expect, in encouraging people to serve, our will have to trust each other, showing true respect and acceptance.

I have considered these positive ways of relating in a meeting context. However, I think we can ask questions of services in terms of the extent to which they support people with mental health issues in these positive ways. The first three, holding attachment and eye-to-eye validation seem most relevant to me to a critique of services. If I just look at the experience I see of people with dementia and their carers, unfortunately I see people feeling many formal services are leaving them very vulnerable, are not there for them, easily accessible, when they feel they need support and do not seem to welcome their enquiries or value their experience. I hope this will change.

'Meet together and know one another in that which is eternal which was before the world was'

In the presence of mental health problems, we may not be able to 'know one another' and to be known to one another in the way we might 'expect'. One might say 'in that which is temporal', sharing an understanding of reality and of one another's needs. We may not be able to establish what we would regard as a reciprocal relationship.

In our meetings we can 'meet together', providing a safe place, being there for and welcoming others, being together as part of and contributing to one community. This being together, accepting each other as whole human beings, whether we 'understand' each other or not, is perhaps the foundation of knowing 'one another in that which is eternal, which was before the world was'. We are living as part of one greater whole.

So perhaps I come back to my original reading 'Friends, meet together and (*thus you will*) know one another in that which is eternal.