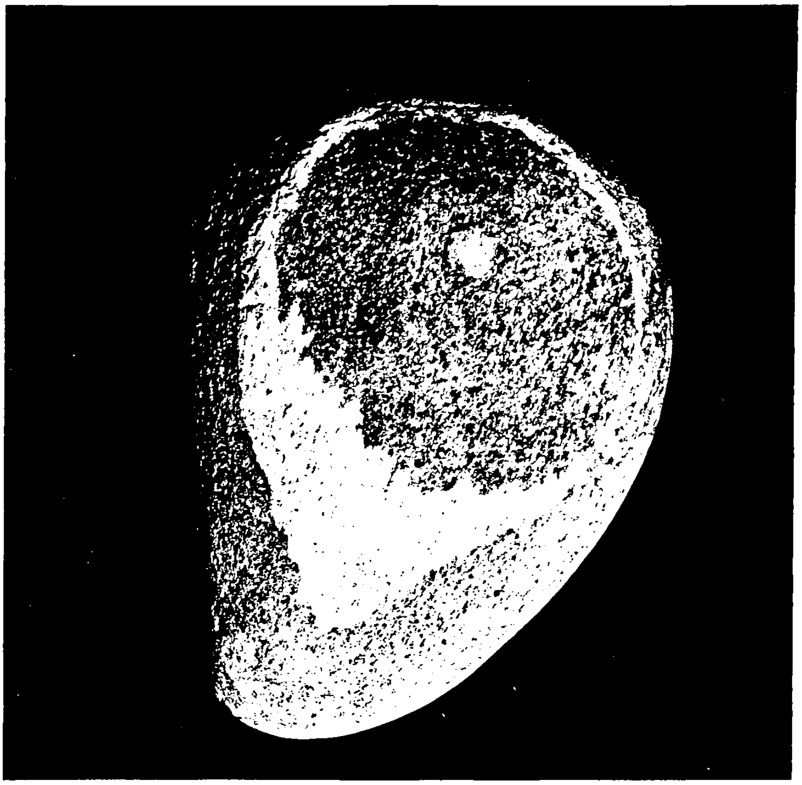

Working with people with loss or threatened loss of vision

MARY TODD

King Edward's Hospital Fund for London

not available for sale 30/12/89

Cover illustration: this symbolic primordial 'stone eye' was found by myself on Machrihanish beach, the Mull of Kintyre, after a storm. The colour, shape form and weight symbolised my perception of blindness, as an artist.

WORKING WITH PEOPLE

WITH

LOSS OR THREATENED LOSS

OF

VISION

MARY TODD

An exploration in caring and counselling recently registered blind persons.

Special reference made to group therapy with recently registered blind adult persons with Diabetic Retinopathy 1977-1986.

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ACKNOWLEDGEMENTS

I am grateful to my family, friends, colleagues, doctors, students and patients for their encouragement or involvement. In particular thanks go to Professor Edward and Enid Hutchinson, who first taught me how to counsel and re-educate persons who needed to have a fresh start in life.

I am indebted to Rev. Dr. Martin Israel for his spiritual direction and friendship

My gratitude extends to Mr. Geoffrey Davies, whose skill as a surgeon, teacher and perceptive 'encourager' enabled this pioneering venture to begin, grow and continue in a medical setting.

The support and cooperation of the ophthalmic surgeons' team, including doctors, secretaries, medical photographer, receptionist and nurses was appreciated.

The liaison training group of social workers for the blind and nurses was a living learning situation - a valuable link which grew out of patients' communication

The experience was supervised by Dr. Irving S. Kreeger - who shared some of the joy and pain and taught me about the reality of care and continuity.

<u>N.B.</u> Wherever possible permission has been given by the students patients and doctors in the presentation of this 'labour intensive' document.

Abstract

In 1977 an exploration into the use of counselling of visually impaired adult persons began in Richmond Adult College, Surrey, where it continued for two years. It moved to the ophthalmic department, Kings' College Hospital, London, in 1980 and continued until 1987.

I formed a group in Richmond for people with visual loss only. In Kings' College Hospital a slow open group was the focus for therapy particularly for blind diabetics. The work, action and outcome of this catalyst is described.

In November 1983 a liaison supervisory training group was formed for social workers and nurses who had become interested in the Project.

This highlighted the gap in service provision.

Benefits varied with individuals and families. The ultimate benefit was that patients were progressively rehabilitated, in that isolation was integrated. Self esteem increased and confidence was restored with reconstruction of life.

Patients were enabled to function better, gaining social contact and friendship. New fields of communication were opened.

PART 1

Description of the work - how it came about and how it worked

The beginning of my work with people with loss or threatened loss of vision first began in September 1974. I became personally interested because of my complete loss of vision in my left eye while driving across Richmond Park to Richmond Adult College, Surrey, where I was to give a series of lectures on the value of play! As a diabetic of twenty two years standing, I became aware of the gap in knowledge, effective communication and action between professional and ordinary people about the real experience of blindness. My interest was particularly with patients whose blindness was part of severe or terminal illness.

My personal experience motivated action research and development of a creative process of spontaneous work which has moved in many directions. It worked because many people shared the struggle to grow through the pain of a rich experience. We gained support and found deep and lasting friendships.

In 1977 in Richmond Adult College, a recently bereaved widow of a blind diabetic drew my attention to her husband's isolation, frustration, general avoidance of verbal communication of changing life situations and inevitability of death at the end of his life. Her feelings and desire to help other people in similar situations further encouraged my action to research into the prospect of integration or disintegration of diabetics who were suffering in similar ways.

As student counsellor and community education coordinator I was able to set up a group. This group of six blind adult students (as well as a guide dog and, the college cat) were either self-referred by general practitioners or psychiatrists who in the past had offered only tranquillisers or sedatives. Ages ranged from twenty-one to sixty years. The group was the centre of a larger group of adult students meeting once a week for the 'New Outlook' rehabilitation programme of liberal studies which included the options of braille, moon (a symbolic system of writing for the blind) poetry, literature, current affairs, sculpture, philosophy and general studies.

The group sessions took place in the lunch break for one and a half hours a week. It was here that the thoughts, feelings and circumstances of those who were blind were to be explored.

The blindness was due to a variety of causes, diabetes, multiple sclerosis or vascular disease. All members travelled to the college on their own. Everyone was trying to come to terms with the effects of severe physical or mental illness in themselves or their families. The format of the group was unstructured.

Thoughts and feelings about loss of vision were expressed through symbolic language for at least six months. The widow responsible for forming the group used the time positively to work through her bereavement. She gave and received help. After three months she left, leaving behind her husband's white sticks. She took with her enough courage to climb to the top of a mountain.

On the surface, the group presented a cheerful facade. Underlying this were unresolved feelings of fear, sorrow, grief and anger, unexpressed in ordinary language. At first these feelings were blocked or denied. Gradually the cheerful response expected by relatives, friends, colleagues and doctors, was given up and members came to terms with life situations more realistically. The work progressed slowly. The educational and social content of the surrounding rehabilitation programme enhanced the quality of life of members of the group. The symbolic language inside the group was intensified for a further three months as some members explored ways of sculpting perfect forms in the sculpture studio.

These sessions were for two hours immediately before the group met each week in the spring term. I acted as an observer in the first, middle and last sculpture sessions, with the permission of the tutor and members. This sculpture group was a catalyst of intensified practical creative ability. The work was experimental and at times, extremely painful. It became art therapy as members not only attempted to cope with finding their way around the hazardous sculpture studio but also experimented in clay, stone and wood. The choice of materials revealed aspects of personality, sensitivity and how blindness had affected members' feelings, thoughts and creativity. The ways in which the materials were worked, revealed a painful struggle to accept and make objects which at first reflected the unacceptable horror of imperfections, frustrations and unexpressed feelings of anger about aspects of blindness which were denied or split off. Gradually imperfect objects in the form of symbolic eggs were created. The sensitive feelings which came up in the sculpture sessions were shared in the group. By Easter a collection of symbolic eggs were gathered together and exhibited in the college. These aroused interest in the college common room and helped to dissolve the taboo of blindness. There were, however, polarities of feeling about exhibiting the eggs; should they be seen as the result of an aesthetic creative struggle, or as objects 'made by the blind'? This topic was aptly resolved by a doctor who had reluctantly joined the sculpture group to keep his blind diabetic wife company. After observing the difficulties of sculpting he commented: "I have always left the sexual activity to my wife before", and thereupon joined in and produced a hard wooden egg covered with very sharp nails. His wife made a soft wooden egg containing nails.

Everyone's pain about blindness was obvious. For those whose eggs were taken home and used as conversation pieces, a healing approach to blindness began to grow in the family. For those who took the eggs home and either destructively smashed them up or kept them hidden, a great deal of therapeutic work had to be resolved in the remaining group sessions.

In two years these regressed primitive feelings were extremely difficult to contain. As a group conductor my inexperience in working closely with people whose sensitivity about blindness was very close to my own unresolved deep feelings, showed that the experimental unstructured way of working was almost too painful. As an artist I unconsciously was working towards confronting the fact of the possibility of no longer having a 'seeing eye'. However the two years intensive group work resulted in support and care with firm friendships established. Loneliness decreased. When the group finished, members agreed to continue their friendships by meeting from time to time in Kew Gardens.

The work of this first group revealed that blind persons lacked helpful information. Social workers had little or no specialised training in dealing with their problems. The average time between registration by the consultant ophthalmic surgeon and contact with social services was at least six months. Doctors and psychiatrists seldom did more than offer tranquillisers, sedatives or anti-depressants.

There was little or no insight into the psychological problems caused by blindness in the family. No one wanted to know or had time to listen. There were many patients but limited resources. I appreciated the medical difficulties. Not only was there a lack of time but particularly for diabetics the prognosis of visual loss was doubtful. The need to steer a course between 'ignorance is bliss' and the painful reality of truth posed serious problems.

At the time I wrote: Group work at its best is like a family tree; where flowers unfold, where there is healing. Time is needed for health and growth. My personal exploration had been through a hope - growth model of working, which emphasised the Pygmalion approach, one based on a human wholeness cycle. I used my creative imagination to visualise people wearing bifocal glasses - where darkness and light would be seen simultaneously. In my perception the lower lens represented the painful pathology of blocked growth while the upper lens represented strengths and potentials. Hope was the energy of change, light was the presence of energy moving in certain frequencies.

My search for a philosophy to help me work creatively led to ask if blind people would need a spiritual dimension in life in order to transcend aloneness and separation. Growth in awareness led me to realise that the analytic uncovering process, based on repetitive working through of past experiences of loss, could lead to clear articulation and satisfactory resolutions. I did not comprehend the extent or depth of the difficulties of working through unsatisfied drives, unconsummated relationships, demands of conscience and needs for restoration of order. The realisation that the first group was supportive for visual loss only, in an appropriate setting led me to consider the viability of a group for persons with catastrophic or terminal illness in a medical setting where psycho therapeutic support was available.

In 1982 the pilot study was completed. This established a prima facie case for a feasibility study of a larger scheme.

In 1983 King Edward's Hospital Fund for London agreed to give a grant, to the Ophthalmic Department, Kings College Hospital, for two years. This was for three sessions a week for one year and four sessions a week the second year. This was for the funding of myself as Co-ordinator of a project which would help people to cope with loss or threatened loss of vision. Agreement was reached that the third year should be financed by the Retinal Fund, Kings College Hospital. The award given by King Edward's Hospital Fund for London was in the first place to be seen as a capital investment in a new pattern of aftercare which would significantly improve one area of health service. The project would contain one study group for patients recently registered blind or partially sighted/blindness any causation); one study group of patients with glaucoma, and one study group for para medical staff. There had been considerable progress in the preservation of sight due to the use of the Argon laser for treatment and developments in surgical techniques and drug therapy for glaucoma. However, little research had been done on the profound psychological and social consequences of patients losing their sight. Nor had there been any developments in new methods of helping patients and their relatives to cope with the impact of loss of vision. Initially the aim was to use individual or group counselling as an exploratory interpersonal research activity, as well as a source of understanding and help for patients, relatives, friends and professional members of staff. As time went on the work with severely regressed, almost defeated patients, changed, as we worked in greater depth.

"The important distinction between counselling and psychotherapy is not a question of territorial preserve, duration of training, or the pre-requisite of a personal analysis. The distinction lies in the therapeutic process itself as a function of depth structuring"*

The first account of the beginning of the group experience shows a beginning of a slow open group which became the centre of the Project.

From July 1982 - April 1985 the group contained twenty-seven blind patients ages ranging from 30 - 60 years. Two patients had glaucoma. One third of the group travelled to the hospital by ambulance because they could neither see nor walk due to diabetic complications.

*Ref. 'Structuring the Therapeutic Process' Murray Cox p.49 p251-256

All patients were almost defeated and regressed, were not only endeavouring to cope with increasing sight loss, plus severe illness but life crises in the present and past family. The motivation to come for 1½ hours each week was extremely strong. The average attendance was a continuous commitment of at least thirty-six sessions. The group was difficult and painful. Members endeavoured to overcome enormous difficulties of mobility plus physical and emotional suffering. The feelings shared were deep and lasting. Difficulties were always present. The support, continuity of time spent in depth relationships changed the group ethic. By 1984 this had changed from 'enhancement of life' to restructure of life. Survival as a blind person changed to living as a person with loss of sight. Feelings of dereliction changed as aspects of living became firmer. Despair became hope and problems or confusions were clarified.

Relationships in this group were very close because of the shared painful interaction in facing loss of vision with the inevitability of death, having shared experiences of loss or blindness in the family.

The focus was always on loss of vision. The group was very supportive for members who also came into hospital for extensive laser treatment or for surgery. The boundaries of the group were difficult to keep. At times of crisis it was essential to involve medical staff, nurses and social workers. At all times the support of the Ophthalmic team and nursing staff on the ward enabled the group to be an integral part of the ward life. The immediate surrounding life of the ward was extremely important to all members of the project. The observations and support of nurses, auxilaries, receptionists, secretaries combined to help patients not only to find self esteem, but enabled and encouraged them to be articulate with other people inside and outside the hospital.

All patients used the group as a catalyst to inform professional and non professional people of the needs of people in similar situations. This was because of honesty between myself and the patients which dissolved professional barriers.

The experience was only self help in that it was born of need and necessity. A great deal of genuine honest painful interaction with a depth of underlying humour and sorrow formed the centre of the Project.

During 1983 there were seminars and talks within Kings College Hospital, with consultants and clinicians, nurses and medical staff. The combination of the results of my crisis intervention work with patients, liaison with social workers and nurses, together with seminars and discussions with generic social workers in Bromley and Southwark, resulted in the formation of a training group in November 1983, until its continuance in August 1986. Membership started with social workers and was opened to nurses in September 1984. The ten members have included two specialist blind social workers, (plus a guide dog) three sighted specialist social workers for the blind, one district nurse, two nurse managers, one social worker with the bereaved and terminally ill and one social worker with severely ill patients. An observer from the Nursing Management team was also included. The main function of the group was a continuing liaison between the hospital and the community. The workers have gone out into Bromley Social Services, Sutton Social Services, four areas of Southwark Social Services, Lister Health Centre, Railton Road Clinic, Dulwich Hospital and Guys Occupational Health Department. The direct crisis intervention work of the members in the training Group resulted in lives of suicidal and severely ill patients being saved. The supportive work with families in acute stressful situations was felt to be valuable by patients etc. The exchange of information, change of attitudes, increase in sensitivity and understanding of members in relation to patients and families showed growth and development.

From 1979 - 85 the group for patients with loss or threatened loss of vision has continued. Ninety two patients have been studied. They were invited to be involved in group or individual counselling or psychotherapy.

The work of the Project has been consolidated and recognised within Kings College Hospital. Information was given when requested. (See 'Insight' a guide for patients with loss or threatened loss of vision) Outside Kings College Hospital the work has been disseminated as follows:-

1983 an article about the work of the Project was printed in 'Kings View' the hospital magazine. In September 1983 there were seminars given to Southwark Social Services Generic Team Leaders and Social Workers.

Similar talks, discussions have been given to social workers in Bromley, Lambeth, Lewisham and Sutton social services in 1984. Liaison and talks with the nursing management team in Kings College Hospital and with district nurses and health visitors in the community health district throughout 1984 and 1985 aroused interest in the need for training in counselling for nurses working with patients and families in acute stressful situations - this interest was not translated into action for financial reasons.

In Spring 1984 The British Journal of Visual Impairment published a letter about the Project.

In June 1984 Dr. Irving Kreeger and myself were invited to the Southern and Western Region for the Blind Conference to speak on the work with blind patients in Kings College Hospital. In July 1984 discussions and talks were held with ambulance drivers about the needs of blind diabetics. These talks were followed up by excellent liaison service and co-operation with the drivers who arranged to walk with patients up to the ward, into the patients group. The work here was gradually eroded because of Government cuts in Ambulance Services - 40% in 1986.

In November 1984 discussions were held at Morley College, London, with Dr. Roger Foggett, Head of the Community Education Department with the view of helping to integrate blind people into the Community within an Educational setting.

Problems arose: a) lack of finance; b) defining the nature of the work eg. "What was re-education? Could counselling or group therapy be within an educational setting?"

Agreement was reached that individual blind patients could use the facilities of the college as a step into rehabilitation and be regarded as valuable student members.

In December 1984 Dr. A. Rawson, Senior Medical Officer of Health Department of Health and Social Security, visited the hospital with Mrs. Mary Jobbins, Social Worker in order to make enquiries about my ideas concerning severely ill blind patients in the National Health Service. Discussion of methods used by myself in the Ophthalmic Department since 1979 led to conclusions that therapy of this kind would be valuable within the National Health Service. The meeting was held in the Department of Psychological Medicine and attended by myself, Dr. Geoffrey Davies and Dr. Irving Kreeger.

This was followed by a dynamic group meeting attended by Dr. Rawson, Mrs. Jobbins, Dr. Penelope Shore of the R.N.I.B. and all members of the supervisory training group.

One result of the visit and subsequent report was that an enquiry was made by the D.H.S.S. as to why Occupational Health Services had been cut within the Hospital and outside in the District. A recommendation was made that the work should go into Health Centres in the Community.

On January 1st 1985 an interview was broadcast on BBC 'In Touch' programme. I described constructive work with patients and families.

Results were that:- a) Patients were put in touch with Consultants particularly interested in disability or rehabilitation, university health centres, pastoral counsellors, or ministers of religion in various parts of the country.

b) Information was given about ways patients could communicate about their difficulties relating to recent loss of vision.

c) Contact was made with rehabilitation and developmental workers, social workers and counsellors in nine areas of Scotland, England and Wales.

d) it was decided to arrange a workshop for professional and informal carers who were working with people who were blind. On 18th October 1985 a workshop 'Psychodynamic aspects of counselling and caring for people with loss or threatened loss of vision' took place in Normanby College, Kings College Hospital, London. Thirty four people attended. The experience was recorded. In August 1986 the leaders sent a report on the day's proceedings to all the members - thus serving to reinforce the day's learning. Reports were also sent to others who were interested:- Mr. E W.G. Davies, Dr. A. Golding, Dr Annette Rawson and Professor Robert Cawley and Dr. Nicholas Temple (Psychological Medicine Department, K.C.H.)

In June 1986 the Project was supported by Mr. Geoffrey Davies, and Dr. John Goodwill for a formal appointment of a counsellor for the blind in Kings College Hospital and outside in the Community. The Project was formally put into new health service proposals for 1987 and was in the last 80 of new proposals. Because of the lack of money in Camberwell Health Authority the request was turned down.

Sir Frank Mills, the Chairman of the Health Authority contacted the R N I.B for financial help towards the appointment of myself for four sessions a week. This request was refused.

Mr. Geoffrey Davies put in a formal request to the Appeals Committee of Kings College Hospital for the continuation of the work.

In September 1986 the Royal London Society for the Blind agreed to fund the cost of four sessions a week for a two year period.

Dr. Nicholas Temple was asked by Professor Robert Cawley to help in the supervision of the work.Dr. Irving Kreeger had retired.

Throughout 1987 I have attended the psychotherapy seminars in the Psychological Medicine Department and this has enabled me to formulate a more focussed structured approach for the work as a whole. I gained a greater understanding and appreciation of the process of working through and resolving in-depth experiences and associated psychological emotional or pathological problems asociated with the onset of diabetes after a trauma.

The work in Kings' College Hospital

The move to Kings' College Hospital in 1980 was first discussed with Mr. Geoffrey Davies, consultant ophthalmologist in the Ophthalmic department. Dr. Anthony Golding, community physician was consulted about the proposed work. Dr. Irving S Kreeger, consultant psychiatrist in psychotherapy of the Psychological Medicine Department agreed to supervise. The proposal was that a pilot study should be undertaken.

It was seen as a research project in which patients could share and explore ways to come to terms with blindness or loss of vision. The words 'loss of vision' were a problem, they were too imprecise. Because of difficulties in contacting patients, partly because of clinicians doubts as to how the work would help patients, it was decided to limit the referrals to those recently registered.

Selection

There was a random selection of patients during the period 1980 - 1985; the majority were eligible when registered as partially sighted or blind. The criteria for partial sight was vision deteriorated to 6/36 in the better eye, and for blind registration vision worse than 6/60, or gross restriction of the visual field.

Most patients were referred by Mr. Davies on completion of the B.D.8 form and after they had been seen in the retinopathy clinic which runs alongside the large diabetic clinic.

Before selection the following criteria had to be satisfied:

The patient had a major problem in adapting and forming interpersonal relationships.

The patient's behaviour revealed aspects which were counterproductive in adapting to loss, loss of vision, self esteem and employment.

The patient needed to have a very strong motivation to adapt to changing physical or psychological conditions.

The patient had a major problem in communicating about his loss of vision - eg. crying in the out patients.

The problems of age, physical health, patient's co-operation and mobility - particularly of patients with amputation or neuritus due to diabetic complication contributed to major difficulties.

Each patient was interviewed at least twice for fifty minutes each time before joining the group. Each patient was invited to bring a friend or relative to the interviews and to the group. This was taken up initially and thereafter at times of crisis.

It was significant that the majority of patients suffered from isolation and loneliness, depression, anxiety and fear of the future connected with fear of total loss of sight, or severe additional illness. They were concerned about communication, confidentiality, doctors' attitudes and so on. The serious nature of the work was summed up by the phrase: 'We don't go out of this world the way as we came in!'

Difficulties and issues about mobility and transport were also raised at the interviews. Only patients who had a very strong motivation to come, and were prepared to commit time to attend, were accepted for individual, family or group work. It was found that help from relatives or friends was unpredictable; patients had a strong need to communicate away from the family and to build trusting relationships. Patients who were prepared to commit time to being in the group needed to be of value to others.

From 1983 - 85 ninety-two patients were referred because of blindness or partial sight and where the prognosis of further improvement in sight was doubtful. Sixty-four were long-standing diabetics with poor prognosis of what was left of their remaining vision and a history of instability or lack of self care.

One third presented a multiplicity of problems, not only physical but of an emotional and psychological nature which affected the prognosis. There was also non compliance with authority and severe social and economic deprivation. In the majority of cases the registration procedure represented a 'cry for help'. Patients with the most severe problems, including stress, anxiety, fear, hidden depression and threatened suicide, received immediate help.

It was based on methods used in benign group psychotherapy and experimental learning; issues raised were brought up by the patients themselves.

It was also understood that whenever there was a need for referral it went automatically to the responsible clinician in the appropriate department. The existential poetic intuitive style was informal and authentic. The pace of the group was slow. In the beginning and centre of the process blindness presented a challenge and meaningful ways of coping with loss of vision were explored in practical and imaginative ways. Throughout the time the gradual opening of trust and communication in sharing deep feelings about personal relationships was reconstructive.

As time passed the group exploration into ways of coping or not coping with blindness as part of severe illness came through the group culture in humour, contrasted with sadness with the emergence of poetry, music, stories, myths, dreams and playing with language. Gradually defences dropped. The intensity of listening and concentration brought members closer together as significant life and death events were accepted, recognised, compared and worked through. The exploration into the meaning of the cause of blindness led to what lay behind the isolation of the individual in the family.

The dynamics of inter personal relationships in a cohesive group with the exchange in giving, receiving, living and loving was a continuing healing process. This enabled members to cope better than before. Involvement and understanding came through the very strong motivation to accept opportunities to go through the psychological processes of mourning not only for loss of vision but for losses in significant past relationships.

Until the group was suspended in the summer of 1987 after the natural deaths of six members and the impact on myself of the blindness of Dr. Irving Kreeger, the intra psychic process had led to integration, concern with change and to growth of inter personal resources. The reconstruction of life however limited with choice of action at home was most important. The majority of patients found what was true and what was false and overcame formidable psychological, intellectual, physical and emotional barriers.

The whole group experience, led to an appreciation and re-evaluation of life as we came to terms with the effects of serious illness, the complications of diabetes with the process of dying and death. Even after the suspension of the group the benefits were infinitely lasting.

It was noted that clinicians' failure to recognise or respond to the psychological effects of blindness or loss of vision increased the patient's isolation and consequently the risk of suicide. The denial of the effects of loss in the patient and the immediate family caused by unresolved losses in the present or the past was also a very important underlying problem which contributed to the risk of suicide.

The pitfalls in the whole of the group experience for myself were in difficulties in continuing to have enough mature emotional resources and wisdom to cope with a dying group and their relatives. The distance between myself and the patients was difficult to assess in order to be objective. As a patient I was too close

It may be of interest to note that the clinical ophthalmic causes of blindness were as follows:

Causes	Number of Patients
Diabetic retinopathy	54
Diabetic retinopathy & glaucoma	5
Diabetic retinopathy, glaucoma, cataracts	5
Anoxia (damage to 3rd cranial nerve)	2
Macular degeneration	6
Violent trauma, necessitating enucleation	6
Malignant meloma necessitating enucleation	2
Detached retina	2
Glaucoma	10

Referrals

During the same period it was discovered that a high proportion of patients registered blind had such long standing problems associated with illness that they were unsuitable for long term group work but benefited from shorter term individual counselling. Improvement in treatment had resulted in fewer diabetics being registered than in the past. The considerable advances in preservation of sight were mainly due to the development of technical equipment, such as the Argon laser and advances in surgical and drug therapy in glaucoma.

The unknown factor was the number of eligible patients who through fear did not seek treatment or registration. It was considered that half as many again could be registered, but for personal or economic reasons did not reveal themselves publicly. A need was found for counselling people with loss of vision in one eye - particularly diabetics where the prognosis for the other eye was doubtful. These diabetics presented a younger age group than those registered due to glaucoma, twenty-five to sixty years compared with seventy to ninety years. Further research work could be done with young diabetics with poor control, who were non compliant to authority, and had signs of the complications of diabetes. This could be a preventative measure if diabetic control was scientifically monitored alongside focused short term individual or group counselling or psychotherapy.

How to deal with referrals was a difficult and challenging problem. The personal contact was the best method, but for this to succeed satisfactorily a counsellor or team needed to be available on a full time basis - both for out patients with gradual or sudden loss of vision and for in patients whose blindness was caused through an accident or trauma or unsuccessful treatment.

After 1984 the assessment of findings from interviews with patients and their families showed a significant change in the category of patient being registered. The majority had severe additional illness, deprivation or isolation. The emotional and psychological nature of these problems affected the prognosis.

Cuts in National Health Service provision and personnel, the industrial action of social workers and others, difficulties in mobility and severe cuts in the ambulance service, accentuated the need for families or friends to instil hope and confidence and to have readily available information.

The Underlying Problem

To meet pressing problems underlying the physical condition was the ambivalence or non compliance towards internal or external authority and unacknowledged psychological trauma associated with the onset of the physical illness of which blindness was part. Fear, anxiety, insecurity and hidden depression were symptoms which stemmed from hidden losses in the past. The fear of isolation caused by less contact with external reality or the external world contributed to difficulties with integration. Some diabetics suffered not only considerable intermittent pain due to raised intra ocular pressure or inflammation, but experienced severe emotional pain.

Even well informed diabetics were worried about becoming totally blind due to inadequate explanations or insufficient time spent in honest communication with doctors. After onset of blindness particularly with those who had renal failure there was a lack of information about future prognosis. Many patients had insufficient confidence to get through the cheerful denials and formal procedures. Those with sufficient money sought advice in the private sector.

They did not know if leaking blood vessels would cause permanent total visual loss or whether their blurred vision would clear at all. They did not understand that the varying levels of blood sugar affected the fluid in the eyes causing difficulties in focusing. In all cases the degree of intensity of emotional pain was related not only to the sensitivity of the patient, but to present life experiences and past unresolved problems associated with loss and separation. In the end the personality of the patient was the most important factor in the healing process.

General objectives of the work:-

. to improve one area of health care

. to authenticate for general use a self-help project which would increase and improve rehabilitation and re-education.

With patients and families the work was intended:

- to relieve suffering, clarify confusion in a positive inter-personal way immediately at the time of registration of blindness thus filling a gap in provision
- to enable patients and families to accept loss and face the inevitability of death
- to enable patients to come out of fear, apathy and anxiety or hidden depression
- to enhance the quality of life and restructure it to foster interdependence: encouraging new ways of communication
- to influence others in wider fields, particularly in professional and informal caring, counselling or psychotherapy.

The method of working was based on a model of a slow open group devised by S.H. Foulkes.*

The structure was a commitment of one hour and a half, once weekly in the Savin Library of William Bowman Ward (the ophthalmic ward in the new block of Kings College Hospital). Six to eight blind people met for as long as they needed to come. Although in general they travelled on their own, they were initially accompanied by a friend or relative and at times of stress or crisis. The trust and welcome established at the beginning made sure that the participants knew that the group would contain painful thoughts and feelings.

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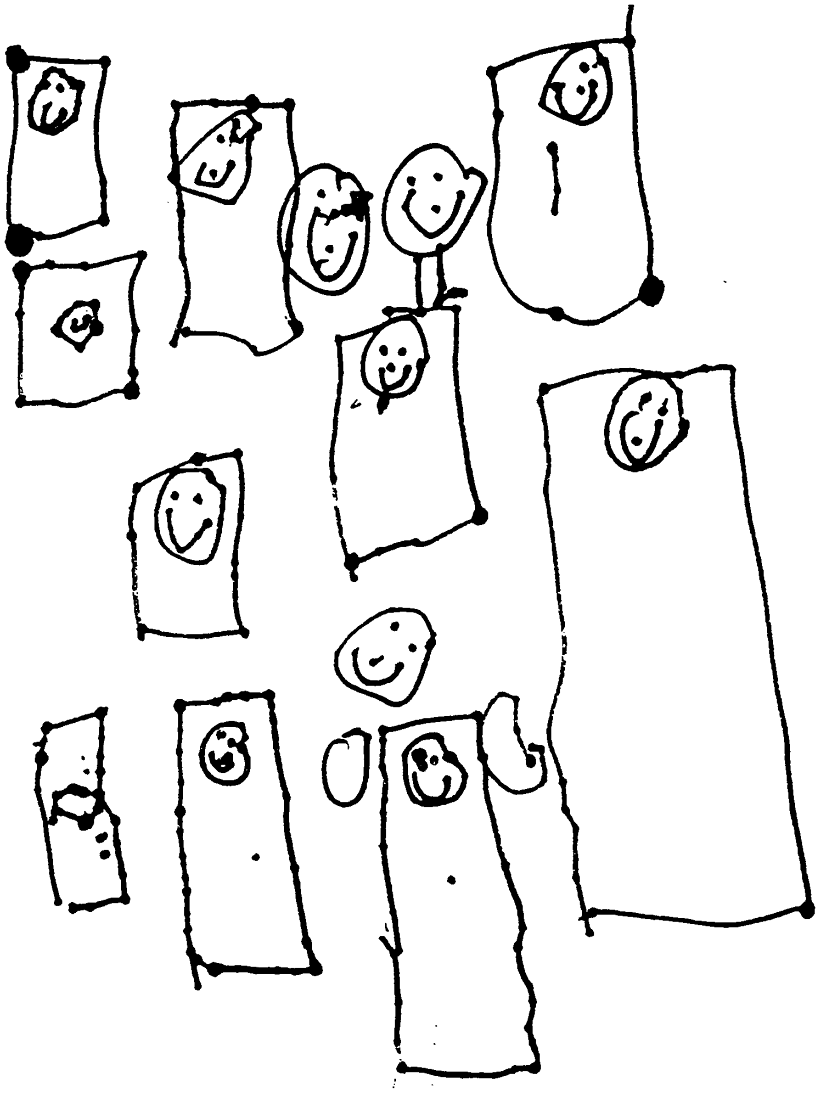
*Participants leave the group at different times and are replaced by newcomers. The group remains, its members change. Ref. S.H. Foulkes, Therapeutic Group Analysis.

to the appalling experiences which were recalled in the group. My poetry was an attempt to resolve my counter transference with some patients who may have been schizophrenic.

I also experienced difficulties in working through my indebtedness to the physicians who saved my life and to the surgeon who not only saved my eyesight but who continually supported the work.

If I had known at the onset of the project what was ahead I would never have attempted the work. Some people have commented that it was impossible. However, the patients and I have all gained a very rich experience of infinite worth.



A child's view of William Bowman Ward, Kings College Hospital.
The surgeon has the only 'ear', the nurse the only 'arms'.

PART II

The Activities of the Group in the Form of a Narrative

Phase 1 February 1980 - March 1983

The word 'group' comes from the word 'knot'. A group can be defined as a number of persons meeting in a given context who interact more / at a deeper level than they interact with people outside the group. How the knot unravells is shown in this experiment in relearning.

The group met for the first time in February 1980 in a small waiting room on William Bowman Ward. Six patients agreed to a weekly commitment. There were five men and one woman, their ages ranged from twenty six to sixty. All except one were recently registered as blind diabetics, their blindness due to diabetic retinopathy with poor prognosis for what was left of the remaining vision.

In the event the two youngest did not come. Both had been ambivalent but seemed willing to explore possibilities. The woman wrote stating that 'as she had never belonged to anything, she had decided not to begin now'. She was unemployed and dependent upon her parents. The other patient expressed fear and anger during the interviews. He also was unemployed and intermittently expressed his frustration by 'getting into fights with the boys' after bouts of heavy drinking. When I interviewed him he expressed views about suicide if his vision should fail completely. (In spite of the small number and our awareness of the difficulties of the dynamics we decided to go ahead and to add to the number as time went on.)

The Members

Victor, aged fifty eight was the founder member. He was advised to retire because of blindness. He was a drayman, a typical, good humoured cockney, born in Lambeth Walk. He had no family history of blindness. His father was a Dr. Barnardo's baby - left on the doorstep of the Dr. Barnardo's Home in Kennington. Victor was the eldest of four boys - all brewers, a widower with no children. In 1978 he had become very apprehensive about his failing vision. He arranged for his cousin to live with him. He also bought a dog. He was fiercely independent and found difficulty in asking for help. He was registered blind in August 1979.

John, aged fifty seven, a retired civil engineer, the only son of a market gardener and married with a young daughter. His grandmother had been a diabetic, blind at the end of her life. He was an intelligent cultured man, very depressed. He stated: 'I expected to lose my foot, but not my vision' and 'Time has come to an end, I can't look any further; time does not matter'. He was registered blind in January 1986.

Bill, aged sixty years, a self employed builder came from a family with a history of diabetes. His mother was R.D. Lawrence's* first patient. She became blind at the end of her life. His sister-in-law was also a diabetic and died soon after the amputation of both legs. He lived in Peckham in the family home and business premises he had inherited. He had a son and daughter.

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*R.D. Lawrence was a casualty officer at Kings when he became a diabetic. He thought he was dying and went abroad. Banting and Best discovered insulin and sent for him to come back. Insulin saved his life. He then devoted his life to helping diabetics, founding the diabetic clinic and the British Diabetic Association.

Diagnosed a diabetic after being admitted to the casualty department in 1978 'with brick dust in his eye', his fears, anxieties and denial prevented him from seeking treatment earlier. He was depressed, almost inarticulate, refusing help and in a state of withdrawn isolation. He had unhappily accepted registration of partial sight 'The consultant wanted to register me but I clung on hope' he said repeatedly. Having been registered blind in January 1980 he refused to go out, repeatedly saying 'I am on my way to the knackers yard'. His wife came to the interview with him. He chose to join the group and travelled each week to the group in a mini cab - although this was financially difficult.

Vladimar, aged thirty nine, a linguist, courier and journalist was married to a nurse. He had no children. He was registered partially sighted in December 1979 because of tunnel vision. He showed great anxiety about his future prospects of employment and fear of total blindness, being left in the dark with no response. Anxious about employment, marriage and isolation, he was glad to explore ways of facing the future.

The four men were going through a period of change. All needed to come to terms with loss of self esteem, loss of work, less money and change in relationships at home. All expressed fears for their future security. All were supported by working wives and found difficulties in adapting to changing roles in marriage.

Communication was difficult at first. Depression and anxiety was manifested by withdrawal, defensive behaviour, or symbolic language. My question 'What would we like to be called?' evoked the reply from Bill: 'My friends call me Punch!' This was the spark of trust which ignited a roar of laughter and started a breaking down of defensive separateness.

Oral dependency needs were openly expressed. 'What kind of food will she give us? Medicine, pills, lager, lemonade or only coffee?' My refusal to provide refreshment caused lively interaction and this developed into sharing when Victor brought bottles of 'Stingo', (barley wine) for everyone. Since the group recognised the limitations of choice for diabetics in a hospital setting, the bottles were unopened but taken home.

Week by week, their language revealed interpersonal conflicts. I learned the language and lore of the group - the Cockney slang, the public and private language, the language of the conscious and unconscious, and the terrible silence of isolation. In the first eight weeks we learned to listen. Each person began to emerge from their regressed and defeated state.

The hospital was a good place to be in. It was perceived to be 'A safe accommodation boat, in the sea of Camberwell Green' - compared with past memories of family reminiscences that the hospital had been like 'a work house in Golden Road' with a collecting box in the out patients for contributions for treatment!

Fears about dependency and inter dependence were freely expressed. 'They do it all for us. We want to do it ourselves, even though it takes longer'.

The effects of laser treatment (for example, difficulties in accommodating conditions of light and dark were compared. This was especially related to the increased risks of driving a car in or around the time of treatment by Argon or Xenon laser. The implications of giving up driving led to heated discussions about power and drive. Once they had accepted the precarious nature of driving, members recognised their displaced feelings about blindness and denying reality. Giving up driving was particularly hard. The added risks of diabetic instability at times of emotional stress were also explored.

The wish for 'authority' to tell them precisely what to do was coupled with anxiety about not knowing whether sight would fail completely. They talked about vulnerability away from the hospital, the reality and likelihood of mugging violence and racial tension in Camberwell. Little by little members lost their inner fears to gain courage from support care and continuous re-evaluation of life.

By Easter, values were more clearly expressed. 'Cor, I won't half miss everyone. It gives me a purpose', said Victor as we parted. During the break John died. The news on the first day back brought shock and numbness. The experience brought home to us all the inevitability and nearness of death and the reality of living and dying painfully as a person with diabetic complications.

The anger expressed about this and other losses in the past almost brought the group to a standstill. It was hard to keep the reality of the situation within the group boundaries, to instil hope and to maintain a working continuity. Avoidance about this loss was manifest. Everyone wanted to escape, to go on holiday. Somehow their sensitive feelings were held and frustration gave way to determination. I said: 'Now, boys do we go up to the top of Mount Everest? or shall we sit back in plushy red chairs and drink milk?' John's words, 'Time has come to an end' were significant. We struggled on.

Vladimar received much help about his conflicts of choice about retraining for a different occupation, being more dependent on his wife and clinging to the past and his occupation as linguist, journalist or courier. He decided to have a final 'fling' by taking a job as a courier to Oberammagau before retraining at the R.N.I.B. centre at Torquay. When he left in June the group knew the route he was to take since it had been retraced many times. His positive move was felt to be good but his departure brought mixed feelings for those who were left behind.

At this time a woman joined the group. Nora had been employed in the needlework room of a psychiatric hospital until retirement at the age of sixty. She had come from Jamaica twenty-five years ago, was married with six children, the two youngest living at home - Anthea aged nineteen and Bunny aged twenty one. Nora was almost inarticulate about her loss of sight, anxious about what she should do 'if the darkness came over her'. She was registered blind in May 1982. Because of her loss of vision she had not been out of the house alone for four months. She was withdrawn, sad, had lost weight and had asked for 'meals on wheels'. She agreed to come to the group after making a 'practice journey to the hopsital' on her own in the last week of June.

The arrival of a woman balanced the group and communication changed. The men became more self assertive, but also gentle and helpful. There was joy when Bill announced that his daughter was expecting a 'chubby!' They were welcoming to Nora's husband and seemed to allay his fears about exploring the meaning of blindness as an illness.

As time passed, increasing warmth, clearer communication and good humour brought confidence. Sadness over past losses were brought up to the surface.

Victor discussed his plans to escape from Lambeth to go deep sea fishing, making euphoric claims of sailing across the channel in a thirty foot fishing boat in August.

We met again in September, the first session was dramatic as Victor described his experiences crossing the channel with three friends, during the French fishermen's strike. His fall overboard, without a life jacket, his realising that fear gave him courage, made the group take him to task for his defensive bravado. This new found ability to be accepted as an equal member of sighted crew forced him to assess his limitations, expressed as 'I did it because I now know I will never do it again!' His courage persuaded Bill to leave the safety of his house by himself and to walk round it. He fell down a manhole but this did not deter other attempts. Soon his vision became very much worse and his feelings were very sensitive.

Norah and Bill compared their helplessness and feelings about the physicians, saying 'There is nothing more they can do for us, they have little time to listen, to explain.' Talking about the lack of privacy and busyness of the outpatients department they found comfort in sharing, gaining enough courage to be able to be articulate in front of the clinicians.

In the Autumn Bill expressed his fears and feelings when a boy; he experienced the dying of his mother as a blind diabetic. My response changed his inner feelings. The tenderness and compassion was therapeutic for the group as a whole. False hopes and wishes for a 'magic' cure disappeared - more of life was reconstructed.

Three days after we parted in December Bill was admitted as an inpatient. The toes on his right foot were ulcerated. He was apparently unaware of the condition.

In January 1981 the group met again to be greeted by the news of the amputation of Bill's toes and to news of the birth of his grandson in King's. In February his leg was amputated.

From January to Easter 1981 the realism in the group was immense. Feelings were displaced onto the facts of inadequacy and reduction in social service provision for the blind. Victor was repeatedly frustrated by the lack of knowledge and information and being 'passed from pillar to post'.

He said that catching a social worker was like 'catching a bleeding leaf'. Only after persistently pestering the social services was he given help and he himself had to state what he was entitled to. The statutory provision was two visits and a yearly review. During this time the group became a knot of painful suffering. It was very hard to hold the deep feelings of anger, fury, frustration and grief and to balance the intensity of unresolved emotions. There were polarities of birth/death, love/hate, creativity/destructiveness, sexuality/impotence, peace/anger, envy/greed jealousy/love but also tenderness and compassion. The whole rich mixture led to a rare closeness and depth of relationships.

At this time all family members came into the group plus the sister of William Bowman Ward. There was much cooperation outside on the ward and the load was shared both inside and outside the group.

Week by week words flowed more freely. To get my own feelings out I wrote poetry which was shared in the group. There was warmth, friendship, courage and good Cockney humour, which went over my head until I bought a Cockney dictionary!

Nora sang spirituals and made up a song called 'The days are getting longer'. The whole group seemed to experience a rebirth.

Bill brought his new leg in a brown paper bag and there was the enormous relief of laughter as I fell over it when I entered the room for the session.

I began to maintain a balance of calmness in spite of the intensity of thoughts and feelings inside the group. New members came and went.

The most difficult time was from January to April 1982. During this time each person reflected the pain of isolation and realistically confronted painful feelings. There was a realistic assessment of values and friendship at home. The words of Susie, a young blind diabetic with a renal transplant summed up the real experience of each member: 'They save your life. Everyone expects you to die and you don't. They don't want me any more as I am. No one talks to me'. The empathy at the time was immense. Each person expressed the feeling that if total darkness came they would like to die.

The intensity of these feelings was not an experience I would wish to repeat. We were all too close.

However, Victor carried or shared much of the leadership with his humour, commonsense, encouragement and forthright language. Barriers of race, culture and history were broken. The violence of the Brixton riots accentuated the vulnerability of us all. Norah, at this time, expressed her transference love for Victor. At home she hatched six brown chicken's eggs on a hot water bottle! The men teased as she sang happy songs and reared the chicks. Her son, Bunny built a chicken house in the garden. The group were fascinated in the change in Nora. Each week we heard about the growth of the chicks and there was a hilarious session when she expressed her fears about the cock, 'Percy' - as to whether he would disturb the English neighbours when he crowed! She named him 'Percy' as his first crow was at 11 o'clock in the morning; there was very much hilarity as to whether or not it was a diabetic cock.

The symbolism, folklore and primitive sexual feelings were expressed with the innocence of childhood. I learned much of the Cockney folklore and history of Lambeth Walk where in childhood members revived memories about events of Londoners with live goats, chickens and activities which I perceived to be of a more primitive tribal nature.

Poetry was written about roses, flowers, fire, fireworks. Music was sung, recorded and sent to isolated bedridden members. Mourning for past losses was worked through and plans for work were made by the majority of members.

Time became very important and appreciation of sound intense. In one session each person brought a symbolic musical instrument. Screech alarms, musical watches, guitars, 'speaking' watches, all were brought into the session to reveal the need for each member to express and respond to sound. We had learned to listen and grown. The ways musical talents could be developed was expressed and went home.

The growth of interpersonal relationships and friendships formed was best expressed by Victor after a discussion about isolation and loneliness associated with blindness: 'Black, brown, red, white, pink, blue, yellow - what does it matter - we can't see?'

In three years members clearly articulated their feelings about the group experience. The closeness there, had been within the tragedies and comedies of many dramatic sessions.

The continuity and care was held in spite of horrifying not knowing and lack of communication with clinicians when 'eyes were no longer seeing and we were registered'.

The phrase about Mr. Davies: 'He did his best - but' had lost its impact as changes in feelings and thoughts inside and outside the group had taken place.

THE GROUP WORK EXPERIENCE

Phase 2 April - September 1983.

In April 1983 the group moved out of a small room into the library on William Bowman Ward. This move coincided with the fact that the King's Fund were to support the work for two years. This was explained to everyone and gave value and esteem to all members. In the period of time from April - August 1983 there was an average of six patients aged 26 to 60 attending regularly each week. Four members of their family came from time to time. A trainee social worker spent six weeks with the group. All members were out-patients except one person who was an in-patient from R.D. Lawrence Ward. All patients were longstanding diabetics except one who had glaucoma. Two members travelled to the group by ambulance, the others came by public transport.

The group explored their own personal history, present circumstances and future prospects through a mixture of fantasy, drama, social history, tragedy, comedy, songs, play and down to earth reality and planning for the future.

The sense of belonging to the King's Fund made the members feel very much more valuable than before. One member, decided not to come by ambulance. She accepted the offer of transport in a car driven by a "Friend of K.C.H." - whereupon she stated that "she felt like the Queen!" The group recalled significant reminders of the past. The drama and social history of each family member was brought in. The group revelled in fantasies of social and economic history of Camberwell and Greenwich. Romantic escapades of Nelson and Lady Hamilton held us in suspense. Jokes about how Nelson's detached retina did not dampen his ardour with Emma, were rife. Each member produced some association or family recollection of belonging to the Royal Family, - at different levels. All discussed how to receive charity. Time and time again the question of whether it had anything to do with love was raised. Real values were discussed freely.

One member recounted how her mother had been a delicate child. She had been chosen to be a ward of Lady P - taken out of her Cockney family and educated at an English Public School. The effects on her education, culture, standards and values came alive again.

At a very deep level all members of the group compromised with the inner emotional and psychological experience of loss in childhood or adolescence when each lost parents or siblings who were blind at the end of their lives. This was the core of the group experience. At times the polarities inside the group were extreme. There were deep feelings as one member described her sister's wedding day, together with the associations of the implications that her blind father could not see the bride. Feelings and thoughts began to be worked through about the effects of blindness plus severe illness in the family now. Another member described how he had been brought up as an orphan in an institution and how he felt that King's College Hospital was his 'second home.' During this time one member worked through his own fears of blindness and of dying as a blind diabetic when he recounted his two elder brothers' blindness, renal failure and diabetic conditions. He also used the group for comfort and to be contained in it while he was coping with very little sight. Mr D - the surgeon, gave him a vitrectomy, which was completely successful.

The group experienced him changing from feeling like an old man to looking, behaving and feeling like a young man again. He worked through his past losses, looked realistically at his present situation and prospects for the future and decided to move away from his mother into a new flat. He felt that he could start again to make new relationships. He was helped by the social worker who came into the group with him and also supported him at home.

In this period of time the group moved continuously from tragedy to comedy. I found the experience exhausting yet energising. There was an emotional ascent. The continuity was difficult to keep going. The polarities of feelings were contained in the cohesive group enabling members to begin to restructure time,depth and mutuality.

The laughter which welled up all the time helped to relieve stress and tension. "Shall we ask the surgeon if we can have 'infidelity' not 'invalidity' benefit?" "Will he send us all to Torquay R.N.I.B. Rehabilitation Centre to find a lady love with whom we can share our feelings?" "Why can't we speak at home?"

Gradually it became very clear why relationships at home helped or hindered members' ways of coping with loss of vision.

The group displaced on to me their anger at being unable to get a satisfying response from people in different situations. "Doctors talk at us - social workers talk past us" was a frequent comment.

The group used me to explore language and to ventilate feelings when they had come across difficulties in becoming articulate in front of clinicians, before authority figures or at home. I found the language of the group puzzling, sophisticated, poetic yet 'down to earth.' Week by week the family joke was the word "Diabetic Retinopathy." As I was the only one in the group who could say it - I was criticised for using university language! "Diabetic Popinopathy, Rotingtopathy, Ratinapathy, Footinratophy, Popinatophy" etc. etc. The play on the words symbolised the difficulties we all had in speaking plain English and in expressing needs clearly. Notably - this language was called "Balderdash" Was it a frothy mixture of liquors, tattle or ribaldry? Associations brought up analogies of Scandinavian mythology. Was "Balder" the God of Peace, of sun, of daylight? How apt was the story of him being killed by the blind war god Höder - at the instigation of Loki (darkness) - yet restored to life the next day.

The examination of the group "mind" - brought great insight "We're learning - using our minds - coming together - not being treated as mechanical objects." The exploration gave us all a valuable experience. It had been a search for a lost part of a family or a whole family - where there were traumatic life and death events - associated with blindness and severe illness. Each member of the group looked realistically at the cause of the "cycle of deprivation" and began to reconstruct a "cycle of affirmation."

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*Cycle of Affirmation. Jack Dominion. Dartman Longman and Todd, 1977.

How life was affirmed and blindness coped with was different for each member.

This was illustrated in 1984 by the husband of a recently registered blind diabetic. He compared the welcome in the group with the home coming he had received from his wife on arrival after walking across Germany as a prisoner of war. The rebuilding process after surviving was compared to the co-operative he had formed in order to build a row of houses near Crystal Palace. Members in the group 'became' the foundation layers, 'the brickies', the 'plumbers' and 'roofers'. Wartime experiences were exchanged and reflected on. The resolution of fears and anxieties were transferred to present day as experiences in coping with 'limbo' situations in facing the future. Strong emotional bonds were formed. The group was particularly supportive to a blind diabetic who had an amputation in 1985. Her suicidal feelings were resolved and with her mother she was helped to face the future. The psychological preparation for loss of limb was difficult and the pain extreme. The group experienced the crises as death and rebirth and contained intense feelings.

This brought reality in reflecting about the psychological meaning of symptoms. Each member faced brutal truth and began to take greater care of each other.

In 1986 the death of the husband of the quietest member was received with shock and numbness. He had assumed the father's role in the family group and had prepared the way for his death by leaving his wife in the care and friendship of the group membership. At this time particularly the spiritual dimension was apparent. Each member grew in self responsibility, self care and found hidden strength. Anger was expressed because of the cuts in the National Health Service.

Regrets were shared that the physicians did not share the deep feelings contained within the group.

Members looked back at their difficulties in communicating in the beginning. Comparisons were made about denial and the collusion of patients and physicians about the inevitability of death - with the difficulty of discerning truths.

Recognition was given again to the fact that until something traumatic happened in the life of the patients the ophthalmic surgeons and physicians had little knowledge of what lay behind the presenting problem of blindness.

The silent cry for help became articulate as the group mourned the loss of a valuable member. His care, humour, friendship and poetry were missed.

Throughout the whole of the group experience I learned a tremendous amount about human courage, endeavour and value in relationships.

THE TRAINING GROUP 1983-1985

A direct result of patients' communication with social workers in Bromley and Southwark, combined with crisis intervention work plus seminars and talks with King's College Hospital Nursing Management Team and Southwark Social Workers Generic Team, resulted in the formation of the training group. This group has met on William Bowman Ward, King's College Hospital for 1½ hours each week, apart from holidays.

The group began in November 1983 mainly because of social workers' curiosity, interest and need to be involved more closely with blind patients. The motivation to help us and to help each other to work within a project was seen as an experiential way of learning. Social workers did not understand how the weekly slow open group of patients was beneficial, although they had seen and heard of it from their clients and myself. My words "to understand group dynamics, you have to experience being part of a group" were accepted.

Membership started with social workers and was also opened to nurses in September 1984. The ten members have included two specialist blind social workers, plus a guide dog, three sighted specialist social workers for the blind, one district nurse, two nurse managers, one social worker with the bereaved and terminally ill and one hospital social worker with severely ill patients. The group also has contained an observer from the Nursing Management Team.

The main function of the group was a continuing liaison between the hospital and the community. The work has gone out into Bromley and Sutton Social Services, four areas of Southwark Social Services, Lister Health Centre, Railton Road Clinic, Dulwich Hospital and Guy's Community Health District. In the beginning, especially, this function resulted in direct crisis intervention work with patients in Bromley and Southwark and was instrumental in saving lives of suicidal or severely ill patients.

The re-educative process was experiential and members have explored feelings, thoughts and actions which helped or hindered communication between blind patients, families and themselves. The interaction of group interpersonal relationships developed into a supportive group, with supervisory aspects. Members have learned how patients feeling of loss of vision are close to their own feelings of loss, bereavement, helplessness and isolation. Awareness of how people can grow through these experiences with continuing caring relationships also developed.

All members found the group a dynamic learning experience, different from the usual case work supervision. Attitudes have changed and the gap between the Hospital and some areas of Social Services was no longer in evidence.

The commitment of time was difficult for each member. It was revealed that the reason some patients had to wait months or years for help was that in all areas of Southwark and Lambeth Social Workers for the blind had heavy case loads. The statutory provision was two initial visits, then a yearly review. One social worker left the group in 1984 for retraining as a mobility officer. She returned to a backlog of work in September 1984 and in June 1985 had only been given time to train two people in mobility. The district nurse found counselling difficult to fit into seeing fourteen to twenty patients per day. The social worker in Dulwich Hospital had a case load of forty patients a month. Social workers for the blind in Southwark were responsible for approximately 250 people in each area. In some areas there was no cover for the blind. (These numbers were approximate).

This group formed as an extension of the patients core group. It developed and grew in many directions so that members became more able to work sensitively with patients and families in acute stressful situations. It has been extremely valuable through the exchange of information, through change in attitudes and has been supportive for nurses and social workers working in isolation. The depths and different levels and ways of working were good.

N.B. This training and supervisory aspect of the Project was financed at no cost to the Social Services or Health Authority. Members came in their own time. This type of labour intensive work cannot rely on good will.

The training group formulated the following assessment of 'job content' for social workers or nurses working with blind or visually impaired people, Chris Brock, Southwark Social Services.

I. Visiting newly registered blind people.

2. Visiting and liaison following referral from relatives, home helps, people with loss of vision, and arranging for examination for registration (BD8) either with hospital, clinic or visiting District Ophthalmologist. (This post was removed in 1985)

3. Discovery and assessment of persons particular needs, anxieties and difficulties.

4. Describing eye conditions in simple non technical terms where no explanation had been given by medical staff. An alternative to this was to encourage persons to ask the ophthalmologist for clear explanations.

5. Provision of aids and appropriate advice about technical aids and mobility.

6. Teaching braille and moon.

7. Extensive contacts and liaison with medical support services, help agencies, charities, educational and social organisations, inter borough departments, self help or support groups.

8. Maintaining case work files, correspondence and all relevant material.

9. Consultation with seniors and generic worker colleagues.

10. Using counselling skills, methods, in working with persons with greater problems than loss of sight.

II. Using greater self awareness of loss and psychological processes of mourning in working with blind people.

I2. Using greater self awareness of the workings of group dynamics and personal relationships in family settings in acute stressful situations.

TESTIMONIAL!

The group of social workers were invited to meet a patient who was in the group of blind diabetics. The experience was described as follows: "At first I was very doubtful. At the time I was very, very, very upset. I couldn't stop crying. Mary knows how I feel so I keep coming. So it's alright. I see her through my 'curtain'. The other eye is closed up. The bad eye is like a window with a murky lace curtain. Light is painful and I wake up in the night wondering if I can still see the light. I get worried but I have calmed down lately."

"How do you see the group?"
"It's all about trust. It is like being a family. It is all about love, sex, marriage, children, dogs - (well, we don't talk about sex much, only sometimes!) I think Dr.- (Diabetic firms' registrar) is wonderful. He is just like my son. They really care here. I can always come. It continues. I am always welcome. It is difficult to keep coming the same time each week, but sometimes my sister brings me and sometimes my husband is here. He helps the others in the group. Mary is just like my mother. She goes through this hospital with purposeful feet. We always hear her coming with her tippety toe footsteps. Sometimes she's angry - my mother's like that. One day my mother marched to the Town Hall when the teacher said I had got 'nits' in my hair - just like Mary goes through this hospital. She doesn't like patients' pain to be ignored - nor the services to be reduced.

She gets upset sometimes; like the day Bill brought us his home grown tomatoes. His wife had got him up at six-thirty in the morning to come to the group. The ambulances had been cut by 10%. His transport was so late - there was only ten minutes of group time left. They put him back into the ambulance and sent him home again with his tomatoes. He gets depressed. He came back the following week and his tomatoes were lovely! That day Mary walked through the hospital with me. She laughed with me and made me feel better, not ashamed about walking with my white stick. We trust each other. I can say everything I want. She will keep it - even if it's terrible. Then she goes quiet or she may have a quiet word with Mr. D. They trust each other and he has a quiet word with me. The group is like home. All the family is in it. Mary didn't know about everyone getting together in a family until I brought our songs. We spent a whole session on them. I felt I was discovered. She wrote the songs down. She didn't know our songs until then.

They were: "I'll come back to you"
"I've got a dear little home of my own - even it's
only a table and chair"
"My mother's ring"
That's how I see Mary, and the group of course.

N.B. The patient's mother was 93 years old at the time.

The following is an example of an invitation to a training scheme

A PSYCHODYNAMIC VIEW OF LOSS OR THREATENED LOSS OF VISION.

The training is for people working with those with visual loss. It is explorative through experiential group and individual counselling/psychotherapy. Professional people can have the opportunity to accept, share, recognise and understand some of the dynamics underlying the surface problems which inevitably arise. The combined experience of shared thoughts and feelings will lead to greater involvement and self-awareness within working situations. The method brings lasting changes instead of short-term solutions.

MEMBERSHIP

This is open to all those who wish to understand ways of caring for and counselling people with visual loss, with the underlying meaning of the experience of blindness in the present circumstances. Those who, therefore, carry responsibility for support, development or supervision of others are welcome. This may include doctors, educationalists, nursing staff, occupational therapists, physiotherapists, counsellors, psychotherapists, social workers and hospital chaplains or ministers of religion.

AIMS

We will look at problems of working in groups with individuals in working situations, with blind people and families, with peers within institutions, within a team. We offer people opportunities to:-

a) Increase understanding of ourselves in relationships with those with visual loss, at different levels and in different settings.
b) Further abilities to recognise and accept responsibility for the growth of groups and individuals at each level.
c) Increase awareness of the processes which hinder or facilitate relationships within individuals/groups/families.
d) Explore and develop skills in co-operation and communication.

MANAGEMENT

It is clear from research evidence that the management begins with the diagnosis of the patient by the Optician or General Practitioner then the Ophthalmologist and Ophthalmic team.

The research highlights the gap of the dynamic psychological, spiritual, emotional or intellectual needs of patients with loss or threatened loss of vision.

Considerations:

1. Incidence of blindness or partial sight.

a) It has been estimated that in Lambeth in 1986 there were approximately 1000 registered blind or partially sighted.

b) In Southwark there were 1,236 registered. (It is not known how accurate or up to date these figures are*[1])

c) It is considered that in addition to those registered there were half as many again who might be eligible for registration.

2. Problems presented by the blind or partially sighted.

Approximately one third of patients were found to be in need of counselling, psychotherapy, group counselling or group psychotherapy eg.:

a) Where the cause of blindness is traumatic - due to violence or accident.

b) Where there is severe crisis in the individual or family coinciding with the onset of blindness.

c) Where there is depression, anxiety or suicidal feelings.

d) Where there is a history of visual loss in the past or family.

e) Where blindness is part of a larger disability, severe or terminal illness causing acute stress.

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*1 Social Services Information - from Records.

3. For most patients, problems arise due to social and emotional isolation. For approximately two thirds of them this may be an acute problem. There is loneliness, loss of self esteem, insecurity, status, loss of employment and difficulties in forming new relationships. These problems are accentuated in a multi-racial society such as Camberwell due to barriers of culture and inequality.

4. The unmet needs for rehabilitation or long term care:

a) Little or no specialist rehabilitation services for the blind or partially sighted in the National Health Service apart from the provision of low visual aid clinics.

b) Lack of re-education, immediate information regarding available benefits following registration procedures, amongst professional workers, the general public and patients.

c) Delays between the registration of blindness or partial sight by Consultant Ophthalmologists and Social Services Statutory Services.
This may be due to financial cuts, large case loads, low priority given to the needs of the blind in Social Services Departments. (Statutory provision - 2 initial visits and a yearly review. Delays from 3 months - 2 years. In some areas of Southwark there was no specialist cover for blind patients)

d) Inadequate provision or availability of mobility training.

e) Social workers for the blind were often classified to be of lower status then generic social workers. This may be due to a lack of a national training scheme.[*2]

f) Lack of resources, time or training in counselling skills for social workers, nursing or medical personnel, specifically related to the needs of the blind or for patients in acute stressful situations.

g) Unmet needs in the community in the care and counsel of blind patients.

[*2] Ref. R.N.I.B. Report on Social Rehabilitation 1985. Dr. Peneleope Shore.

h) Potential sources of rehabilitation in Occupational Therapy is largely untapped due to financial cuts in the Hospital and Community. At the present time these services would be unable to cope if patients were referred, e.g. in 1984 only two blind patients were referred to K.C.H. Occupational Therapy Department; one was suffering from mental illness and the other terminal illness (Occupational therapists became aware of the gap in provision and for further training in caring or working with blind patients)[*3]

i) General Practitioners stress that the decrease in time spent in communicating with patients results in patients being left with problems which might otherwise be resolved.

j) Research findings show that patients are attempting to attend out-patient clinics, seeking help for problems which could be dealt with by social workers.

k) There are unmet needs in counselling blind patients and families in Health Centres for long term care.

l) There are special problems associated with the stigma of blindness in the multi-racial society of Camberwell - where there is violence, mugging, racial inequality, culture or lack of equal opportunities. The vulnerability of blind patients as victims of violence alerted some district nurses, G.P's and Psychiatrists to what was known as the 'Peckham Syndrome'[*4]

m) There are unmet needs in blind patients and families due to very severe social, physical and economic factors; eg. blind diabetic Jamaican unemployed men.[*5]

n) There are communication and language problems in minority ethnic groups.

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*3 Information from Senior Occupational Therapist Camberwell Health Authority.

*4 Information from Dr. P. Robinson, Psychiatrist. The Maudsley Hospital, London S.E.5.

*5 Social Services information.

o) There are special problems in the planning and long term care of the elderly blind or partially sighted; particularly patients who have blindness due to glaucoma.

Management Strategy

Immediate action of referral at the onset of visual loss is important. Likewise, the involvement of patients with relatives and friends can begin ongoing support and continuity of care. There is a need to be alert about failure of this kind of support. The problems need to be assessed and clarified before being acted upon.

Communication involving patients, families, G.P.'s, opticians, ophthalmologists, occupational therapists, health visitors, district nurses, social workers, can bridge the gap between Health and Social Services.

A source of help in future planning in the management of visual handicap can be in the field of counselling, psychotherapy, group counselling or group psychotherapy, family therapy or community psychiatry. This can be used to initiate new methods of helping patients to cope with the psychological, or psycho/social effects of blindness. This can be regarded as valuable, timely, in-depth training, if recognition is given by National Health Service Management.

The reduction and cuts in all service provision make this work even more important than when it began in 1977.

Financial resources:

- Regional, Community, Hospital, Health or joint funding with Social Services
- The RNIB and the Kings Fund
- The British Diabetic Association
- Voluntary and Charitable Societies
- Individual donations

Organisation.

The work can be assessed in hospitals initially:

Implemented to establish:

- preventative work - short term focussed problem orientated groups
- work with people with gradual loss of vision
- work with people with traumatic sudden loss of vision
- work with people with personality or deep psychological problems or special problems associated with illness for example diabetes.

How could services for the visually handicapped be improved?

There is a need for financial resources to be shared between Health, Social Services and voluntary bodies. Improvement in liaison, effective communication, adequate information and training in group counselling/therapy leading to, or running alongside rehabilitation, can be economic in long term care of blind patients with their families.

Improvement in health and educational care of these patients might be extended through the extension of the Kings Fund Project if financial resources are made available through the District or Regional Health Authority or through an extension of the Kings Fund Project into the Community - to cover other teaching hospitals in the Greater London Area. The Project in Kings College Hospital has evolved from a small beginning - but has uncovered areas of severe deprivation.

This is because the work is direct action straight from the consultant ophthalmic surgeon - with the patients co-operation - to myself - with the involvement of the family or friends.

Future Strategy

- the development and increase of public awareness of the contribution of creative spontaneous work of integrating people with visual loss, particularly if this is part of serious illness.

- the development of existing and new channels through which information and support can be made available to professionals, all carers and blind people
- the wider dissemination of information and training resources
- the creation of specialist trained counsellors to fill gaps in existing resources in London eye and teaching hospitals

Implementation (see considerations in management)

To establish:

- workshops similar to 'Psychodynamic aspects of caring and counselling for those with loss or threatened loss of vision
- Working parties on future planning of effective preventive work with people with a high risk of blindness, for example, unstable, non-compliant diabetes, glaucoma patients
- a support unit to undertake development work for blind inpatients and outpatients, interested professional and voluntary bodies to increase the effectiveness in which needs of the blind are met.
- a national forum to contribute fresh ideas and implement the type of work begun in Kings College Hospital.

PART III

CODA

It is Faith that illuminates the Future, the faith of everyone concerned, the essence of good medicine. It manifests itself in confidence trust and close relationships and in Peace.

> "The deepest thing in our nature is this dumb region of the heart in which we dwell alone with our willingnesses and our unwillingnesses, our faiths and our fears. As through the cracks and crannies of caverns those waters exude from the earth's bosom which then form the fountain-heads of springs, so in these crepuscular depths of our personality the sources of all our outer deeds and decisions take their rise. Here is our deepest organ of communication with the nature of things; and compared with all these concrete movements of our soul, all abstract statements and scientific arguments - the veto, for example, which the strict positivist pronounces upon our faith - sound to us like the mere chatterings of the teeth..... These are my last words to you: Be not afraid of life."

Extract from 'The Will to Believe' chosen by William James' brother the novelist, for 'The Spirit of Man', an anthology in English and French from the Philosophers and Poets by Robert Bridges, OM. 1915. Poet Laureate. Longmans, Green and Company, London.

'Feeling Ways into the Visible Darkness'

'We listened to the patients. They told us the diagnosis'
'We speak through each other'.

The Blind Group Experience

These truthful, artistic, poetic communications, are
immediate objects of perception. By expressing
creative psychotherapy in this way, there is the
experience of emergence. It is not sublimation.
The words reveal natural communication within a
dynamic space. They emerge from the paradox
of loss of physical vision with the gain of perception.
The words express genuine human needs.
Can these feelings and thoughts reverberate;
be felt, be verified and clarified?
Good psychotherapy resolves the experience of abandonment.
Tender love is the centre. Care encircles.

"Feeling my way into the visible darkness"

1979

No eyes?

No mouth?

No speech?

Emotional?

Inarticulate?

Unconscious?

Pain

FEBRUARY 1980 - MAY 1982

A Group Experience of Feelings, Thoughts Movements and Soundings.

When Igor Stravinsky wrote his 'Rite of Spring', he just wrote what he heard. I have allowed this group of blind diabetics to speak through me. How these life events of loss and prospect of death affected us is here. The intensity of pain or joy has gone with these Pascals' thoughts.

"I have come to say good-bye - when the darkness comes over me."

Diminished
The children ran away
Away to cavernous mountains
To Hide in beds of grief hidden in beds of violence
In Brixton, Camberwell and Peckham
Afraid to go out
Only to the church or to the hospital
To the "push and pull" to drown the sorrows
In bottles of 'Stingo'
To throw darts into boards unseen
Shouting "no one cares" at the conductor
Chasing social workers just like bleeding leaves.
Unable to recognise the blindness
Hidden behind the smiling diabetes
Unknowing uninformed officialdom
Passing the buck or cushioning the pain
In welfare benefits.
We are all guilty of denial.

Diminished

The children ran away

Lifting weights, stumbling into disabled races

Afraid to cross the road, the wife, the friends

Afraid to speak, to say, "I'm on my way to the knackers yard".

Just in case they leave us

Just in case the cheerful denials crack

Just in case they think we're cowards

We cross the English Channel in boats of black

Slip overboard, see nothing, sinking, pressing, pulling

We rise up from the cold cold sea, to learn how to care

How to care for ourselves and for each other

How to go out of the group in a different way

How to be a guide to travellers to Oberammagau

Learning the route by heart planning the journey

Hoping for miracles - for pain to disappear

Hoping for flights to Rome where the Pope kisses feet

Hoping our feet won't be cut off

We're not guilty of denial! OR are we?

Diminished

The children try to stop running away

Continuously coming week by week to the group

Learning to speak to care compassionately

Self understanding through fire, pain, hunger, thirst, cold

Re-education through waiting, listening suffering

Learning to listen in a different way

Moaning, groaning, whistling laughing

Backwards, forwards, upwards downwards

Moving

Hearing how mindless bodies are sent

From pillar to post

Hearing the words "DIABETICS DON'T FEEL PAIN"

EMOTIONAL, ORGANIC, INTELLECTUAL SPIRITUAL?

The tears seep through the night

Into Starklight, darklight, blurred light, clear light

We press the watches, (gifts of blindness) for attention

Press continuously to know the cost of time

Time to live or time to die?

Time to press the alarm to end the group

Hear or block the audio announcer

Repeat the time

Press the screech alarm for attention if attacked or

Seized inside or outside the group

Hidden in pockets, hidden in humour

Hidden in Enfield Brixton Clapham

Hidden at home, in bed, in hidden depression

We're all guilty of denial

Diminished

The children stop

In a moment of time

To share the most intimate moment of all

The pain of aloneness

VOID

"There is nothing they can do if we want to die

We have no right to choose

ALONE

"How can we speak if they don't want to hear?

How can we stand if our legs are cut off?

How can we see without   within

How will we die?

We all fail to hear ourselves - to forgive"

<u>In our imaginations</u>

Diminished but renewed

The children can go

On top of mountains

The winds blow open into gardens incensed in

Clouds of mist

Eternity

Silently the music sweeps us to harmonious union

With soul upon soul upon soul

Intermingling

As petals of lotus flowers

Fall into silent pools of healing

Beyond unknowing death

Renewed

Now we can

Choose to stand, walk or swim,

Face our fearful, beautiful intuition,

Share the painful reflections,

Undoing our isolation,

Just a little.

How can we

Clarify distorted soundings

Uncreated

Movements, flowing, gliding, playing,

Again?

Below, the supervision room moves into sound
Unceasingly playing, the mute guitarist accompanies
The mute pianist to lift the load of music back
To understanding the silent music flowing underneath
Underneath the black diamond Pavan mine.
Mine dead, infant, father, mother, brother, sister, wife, husband
Unconscious, pathological songs without words
Failing to mourn, failing to mourn
Failing to spring to life again.
Where is the completion of the black and white?
Where is the pavan with the galliard?
In the jungle the red and gold hibiscus flowers
Just for a day at a time
Always accepted, needed, tended with compassion
Growing upwards through the darkness
Into the light of day.
Recreating the energy of hope
OF RESPONSE
Who is Responsible?
We all are

A religious experience of loss of vision.

A reflection by a blind glaucoma patient.

Anon.

1982.

'I am in intense pain due to intra ocular pressure.
I cope by meditation. I lift my soul to God.
There is a timeless moment.
No past. No future.
Stillness is safe.
Although the pain is intense, my comfort is to be
'In tune with the infinite.'
I visualise light, pouring through the windows
of my soul.
"High as heaven and broad as truth itself."

The doctors say. "There is nothing more we can do."

1983.

This existential question was explored within the group.
The reflections of our experience brought an answer -
That positive thinking takes time.
To put positive thinking into action takes longer.

'We felt alone
In the hospital
Where there was nothing more they could do.
But was there nothing we could do about blindness?
We can accept, hear, meet again
Stand before truth in stillness
Moving silence into words
Uttered more beyond than behind.'

The importance of communicating and working with an in-patient on a ward.

June 1983.

(Anon)

No voice.
No breast.
No womb.
Sight failing.
Heart failing.
Failing.

'Come close,
Hear my pacemaker.
Hear my whisper,
"I might die tomorrow."
You are my mother,
Loving me
Back into life.
Singing, singing.
Walking in the woods with me
Showing the way to go,
With your white stick.'

These words describe experience of words and action involving myself, patient, and nurses

July 1983

'He cried.
Because I couldn't see him
Wave goodbye
As he went home
Without me.
We sighed.
We spoke in whispers
Until she made me laugh!

Mary laughed with me,
She heard me sing,
"With mi Shillelagh under me arm
A twinkle in mi eye
I'm off to Tipperary in the morning."
My fear of death went as we laughed together.
No one could face me
Or speak of it until my sight failed.'

Two Worlds

June 1984

(Anon)

Not knowing
This little black world of pain
know
Everyone is at a distance

No one enters this little black world
With me
I know
Everyone is at a distance

Now I come out
At last
I know
omeone is with me.

It seemed such a long time
Until
I remembered
The first thing late
Was, THE MOST DELICIOUS STRAWBERRY
I ate, the best ever
When my mother came to see me.

They know, now, something of
This little black world of pain
I know now
EVERYONE, EVERYONE is closer.

The doctors said
'Didnt you know you had Marfans syndrome?'
No one ever told me
The reason I was different
From everyone else!

'My feet bled.'   October 1984. This patient died. She was not alone.

My feet bled.
Into the thunder headed poppies,
Strewn across the ward.
Our question marks in hands
Hold, yet pre empt our mortal pain.
Is freedom lost?
OR does it tremble?
We flow inwards.
The brink of passion moves our silence upwards.
The sight less eyes inwardly bleeding
Delineating lace curtains
Stain out the light of reason:
Timeless moments, pierced by sounds outside
Screaming, Shouting, "Where am I?"
"I am ill. I am ill. I am ill."
All surrounding, confusion, darkness.
"Take me home, Mary belle.
You have such a beautiful face.

Thank you for coming, Mary belle.
I will see you soon.
You have saved me from mental collapse."
The family said:
"How did you do it?"

Individual Experiences

The following individual accounts are experiences in life where blindness is present. They illustrate the way I can work with some patients. A poetic visionary style is shown. Both were written immediately after individual interview sessions of fifty minutes in duration.

The essence of the fusion between the blind patient and the professional therapist is contained within each. There is no ambiguity and no distance. The growth of perception, depth, concentration and sensitivity develops greater self awareness and order.

The account of 'Philomena' shows how an individual struggled to survive against all odds. The motivation to keep coming to the hospital was tremendous.

My illustration of 'Beatrice' is more poetic in that the words reveal a musical mood, rhythm, pattern expression and harmony. The experience of reverie in expressing innocent childhood images after the painful fact of blindness, went a very long way back.

The importance of on going psychotherapy in the National Health Service

Philomena. Age 54 years.

"In January 1985 I thought I was dying of cancer.
I had both breasts removed.
I really didn't feel worried about dying of cancer.
The mastectomy counsellor couldn't understand why.
The Professor advised me to retire.
I needed to go on working. I was divorced.
I was very depressed about going blind.
I had diabetes and my sight completely went in one eye.
When the other eye began to haemorrhage I felt depressed.
Complete darkness and no hope for the future was horrific.
My son rang the hospital for me to see the eye surgeon.
He registered me blind.
My son and I talked to Mary about how we were feeling.
For three months I explored how I was coping or not coping.
I calmed down and found friends in the group.
Little by little, slowly, I learned to trust again.
Mary taught me to calm down.
I said to myself: "Stop. Think. Go slowly, slowly, slowly."
My son lost his job. He did the housework when I was at work.
I tried to rebuild my life again and survive.
In the mornings I set off earlier than usual so that I could take time.
Each morning before I went into the shop where I worked in Regent Street
I went into a church to pray and to calm down.
My temper kept welling up,
As I crashed down the crystal vases on the counter in the shop.
As I made the tea and felt my way downstairs
Wobbling, spilling the manager's tea.

As I tried to go on, I covered up my pain outside.

The group knew and got my feelings out little by little.

I found friends struggling to survive like me.

In the Summer I felt that life was unbearable.

Each week I saw Mary to keep me going on.

I remembered what made me panic in the past.

In January 1986 I got pneumonia and bronchitus.

My good eye started to bleed again.

The dog died and the kitten was run over.

My son and I saw Mary together.

The surgeon said: "that there was nothing more he could do".

I felt even more despairing. I couldn't sleep.

There had been little help from the Social Services.

I went to the G.P. who gave me sleeping pills.

I thought I would take the whole lot and everything would end.

Mary and the G.P. got together. I didn't take the pills.

The Social Services were contacted again and again.

The Family Service Unit was contacted.

I kept going to the group all through the winter.

A member died. He had pneumonia and cancer.

His daughter had to get him into hospital and wheel him in a chair

- to the outpatients.

The ambulances had been cut. His blind wife went with him.

The group were upset. Mary was upset.

We missed them in the group.

Somehow I kept going. We all helped each other.

I needed mobility training. Why could'nt I have mobility training?

The eye surgeon kept supporting us.

I had seven months off work.

I was sent to a Day Centre and treated like a three year old.

In September I went back to work.

It was wonderful. Everyone was pleased to see me.

Even the manager hugged me.

I got a taxi there. One of my friends went home with me each night.

It was a long way back from Camberwell to St. John's Wood.

Everyone helped me and I felt so happy. The group was happy.

After three weeks I felt ill. I couldn't breathe. I couldn't work.

I was admitted into King's. I couldn't hardly see anything.

My son cried and cried and cried.

All the group consoled me, and cared and helped.

I don't know what I will do in the future.

I'm glad I went back to work though.

Beatrice. Age 102 years.

This active, lively lady fractured her leg after falling off a bus.

It was discovered that she had cataracts!

She shared her wisdom and philosophy.

"My name means happiness.
Some things come and some things go.
I am interested in what is in between
and why sometimes nothing happens in between!
I sit and think and dream
I still haven't worked out how the world has come about.
I think about the beginning, the end and life in between.
I am quite happy to die. Everything is arranged.
All my family have gone through the open gates.
I will be the last. Then they will shut.
Won't that be lovely?
We are all alone, but we flock together in the end.

My life has been very wonderful,
although it's been a hard slog.
I was the third of seven children,
born in an Oxfordshire village.
I liked the fullness of buttercups and daisies
gleaming in the sunshine in the wet meadows.
When my mother was ill, my sister and I
walked through the gleaming wet meadows
miles and miles to get medicine from the doctor.
We were very small.
We were afraid of nothing except the large cows!
In the harvesting we used to hide
under the large stooks of corn.
It was prickly and hot but we liked it.

On Saturdays we watched cricket on the green.
All the villages had teams who came to play.
We liked to have tea and hear all the news
  of the surrounding country matters.
On Sundays my father took me to church in Oxford.
He left me there while he rang the bells.
There were four bells, which rang out across the meadows.
I was very small, so small I couldn't see over the pews.
When the parson called out the number of the hymn
  I used to call: "I haven't got a number". No number,
  no hymn book, no-one taught me to read.
I slid down under the pew
  and hummed all the tunes,
  just as I have ever since!
I have always wondered how things happen in between
  and sometimes nothing happens in between.

I wondered how things happened in between people.
When one of the Oxford students fell in love
  with a village girl with golden hair,
  he didn't marry her because he would have lost his income.
He loved her and they had three children
  then she wasn't so beautiful, but he didn't leave her.
Wasn't that lovely?
How do I manage with my blindness?
I just get on with living.
I get into a mess.
Then I have to straighten things out.
I always remember to put things back
  in the right place.

The trouble is, I have to put my feet up now.
So I sit and think and dream,
  how some things come and some things go.
How interesting it is between us all again!

The following reflects feelings following the birth of a blind baby born prematurely (birth weight 1½ lbs) Her mother expresses how she came through the experience.

September 1986

Ni Brook (little water)

Did you know
when I conceived her
Dark forebodings
Seized my mind?

Filled my heart
With fear and trembling
Worrying, wondering
What I would find?

At her birth
I cried out harshly
I don't want her blind
I don't want her -
Part of me as blind
As that?

Then I walked beside the water
Stumbling onward
Against the stream
Wishing, thinking, crying,
Sighing, madly wishing
That she had not been mine.

She could not see
She was not whole
Did she have a tiny soul?

The eye surgeon kindly
Told me what I knew already
She could not see
Would never see
Never, never see a star.

He eased her pain
To stop her cries
My heart grew calm again.
Time passed
Oh so slowly
I kept asking questions
Questions, questions
More than I had asked before
Consoling answers comforted me
But did not heal the pain.

Then I asked
How I could sing
To my baby who is blind?
How could I sing
"Twinkle, twinkle little star"
If she would never
Ever, never, never,
See a star?

How we struggled
To discover
How to play and sing again.
Loving part of everyone's wholeness
Brought me back to Wales and home.
Finding music flowing onwards
We will teach her to belong.

What Does the Patient Say?

The essence of the work is contained in these anecdotes.

1. I wanted treatment and they put me on a diet.
2. No one cares. Chasing a social worker is like chasing a bleeding leaf.
3. We want to do it ourselves but they do it all for us.
4. They save our lives but then no one wants us.
5. The G.P. said, "what do you want me to do"?
6. The trouble with my wife is me. It's hard to live in limbo.
7. Blindness is the black hole. All the pain goes inwards.
8. I knew I felt better when I came out of the house and walked all the way round it. I fell down a hole and the workman called me a 'blind git'.
9. Each day I look in the mirror to see if I am still here.
10. When I look down blue tears are running down my face.
11. The hospital is a safe accommodation boat in the sea of Camberwell Green.
12. I wake in the night wondering if I can still see the light.
13. He explained it all to me. He didn't know whether he could repair my eye or not. I can see you have got a face now!
14. Outside we don't look blind. Inside ourselves we look through a bleeding curtain.
15. I went into the garden with my magnifying glass to see the flowers. The five year old next door asked me if I was looking for beetles or spiders! Now I've got a friend.
16. The social worker didn't believe my mum can't see. So I brought her to the Outpatients to ask for a white stick. They sent me to a shrink because I wouldn't go to school. I was worried about my mum.
17. My mum would like to come to the group but she can only just keep going.
18. We don't go out the same way as we came in.

'All illness occurs within a network of inter personal relationships'

Dr. M. Foulkes

The manifold variety, depth and extreme severity of physical, emotional, psychological problems of group members, inside and outside the group experience, often impeded acceptance, reconciliation and creativity. The words I listened to illustrate all our greatest fears - that of dying in abandoned useless isolation.
'Part of us dies when we lose our sight'.
Time and time again we heard the cry
No one cares.
We have to put our feelings into the space.
Our experience reveals that in spite of extremes of suffering our time together
'made some of us feel better.

There is a need for all people to come together to contribute at different levels inside and outside the National Health Service.

The poetry seems to be 'words strung together.' - over the period of time 1980 - 1986. I have selected these contributions from ninety two patients. They must be considered within the context they were written.

BIBLIOGRAPHY

1. "Identificatory styles in depression and grief"

J.H. SMITH — International Journal of Psychoanalysis 1971
52-259-264

2. "Separation anxiety. An aspect for search for a lost object"

C.M. PARKES

"Studies of anxiety"

J.M. LADER — Special Edition No.3 British Journal of Psychiatrists

3. "A retrospective study of blind diabetic patients"

J.W. BERKOW
M.R.G. SUGARMAN
A.E. MAUMAREE — J.M.A. 193-872 1905

4. "The newly blind, mental distress and somatic illness, disability and management"

FITZGERALD — Ear, Nose and Throat Monthly 52-99-102 1978

5. "Group Therapy in a Rehabilitation Programme"

New Outlook 64-237-239 1909

6. "Studies and Research in Attachment Theory"

J. BOWLBY

7. "Guidelines for the Psychiatric Referral of Visually Handicapped Patients"

GEORGE ADAMS MD
JEROME T. PEARLMAN MD
SHERWIN SLOAN MD — Canadian Psychiatric Association Journal

8. "Psychology of Blindness"

WERNER MD (SAN FRANCISCO CALIFORNIA)

9. "Blindness - some psychological implications"

DAVID KEEGAN MD
P.G. DANIEL
TIMOTHY GREENHAIGH PhD

10. "Group Experience"

LIONAL URGEO (Analyst) MD

Copies from Department of Ophthalmology, Jules Stein Eye Institute, School of Medicine, Los Angeles.

11. "Primary envy and the fate of the good"

MARY WILLIAMS London

The Journal of Analytical Psychology - Vol.17 No. 1 Jan. 1972.

BIBLIOGRAPHY contd.

12. "The Death Instinct and its Relation to the Self"

ROSEMARY GORDON London

The Journal of Analytical Psychology - Vol. 6 No. 2 July 1961.

13. "Cycles of Affirmation"

JACK DOMINION Dartman, Longman and Todd, 1975.

14. "Structuring The Therapeutic Process"

MURRAY COX Pergamon, 1978.

15. "Group Analytic Psychotherapy"

S.M. FOULKES Interface

16. "Cycles of Affirmation"

JACK DOMINION Dartman, Longman and Todd, 1977.

17. "The Spirit of Man"

Compiled by ROBERT BRIDGES Longmans,Green and Company, London, 1915.

APPENDICES

'Psychodynamic aspects of caring and counselling people with loss or threatened loss of vision'

Workshop held on October 18th, 1985
at Kings' College Hospital, London

Leaders: Mrs M. Todd & Dr. I.S. Kreeger

The Workshop in Retrospect

The day began with the hope that there would be three group experiences of what it was like to lose vision.
Aspects of motivations, beginnings, communications involving the whole person, "not just eyes", opened up channels, the themes of which resonated, developed, moving to and fro throughout the day. Contributions, interactions came from members of a large group containing sighted and blind people with a few guide dogs. 34 Members travelled from Scotland, the north of England, the Midlands, the west of England and central London. They represented medical, social, educational and voluntary people who were professionally, formally or informally working with blind people.

First Sesstion

Blind People and Families

Points raised

* Adaptation to blindness - Was it linked to childhood experiences?
* Did these experiences affect the whole of life?
* Were we alert to the needs of the deaf blind?
* Were families over protective, divided, or understanding?
* Initial problems in motivating blind people.
* Psycho social problems involving the family.
* How to survive and be treated as an ordinary person in an ordinary world.
* How to begin

The large group struggled with frustration and were hungry for clear, concise statements about the aims, objectives and methods used in Kings College Hospital. The indirect leadership contributed to the explorative nature of the work. The group wrestled with the difference between problem orientated counselling and the freedom of personality orientated group psychotherapy.

Lunchtime at Kings College Hospital was a time of expansion, informal conversations and many contacts were made.

The group became closer after lunch, as interpersonal relationships developed.

Second Session

Blind people in medical or institutional settings

Points raised:

* Difficulties in privacy and confidentiality in large in-patient wards or busy out-patient clinics.

* Boundaries of time, depth and mutuality in large hospitals where there were not only mobility problems but also difficulties in establishing effective relationships with medical personnel.

* Expectations inside and outside the group "family setting" - the 'stigma' of blindness.

* Aritistic, creative, and practical ways of working with patients whose blindness was imminent.

* The function of dream work in resolution of anxiety about blindness.

* The process of mourning, anger, pain, numbness, grief, sorrow, acceptance.

* Coping with personal feelings of anger, with non-communicative doctors

* Loss of vision may spark off anger and a back-log of problems in relationships.

* The extent to which ophthalmic surgeons kept their involvement with the counsellor.

* Surgeons' sense of failure about being unable to save sight was brought up by blind members.

* The difficulties, limits, defences of doctors spending time counselling or talking with patients

* The reluctance of some diabetic physicians to spell out diagnosis or prognosis for patients with diabetic retinopathy.

* The need for interpreters in hospitals for the deaf blind was important to families where there was retinitus pigmentosa.

* The need to demonstrate the value of counselling in medical and institutional settings was legitimate.

THE FOCUS OF THE WORKSHOP HIGHLIGHTED WHAT THE LEADERS HAD FOUND - THE NEED FOR AN ONGOING CARING COMMITMENT.

* Involvement of friends, families in group work initially or at times of crisis resulted in the patient being able to cope at home, or work, towards having enough inner resources to cope alone.

* Identification with others struggling with fears about similar illnesses or worse could fulfil a need to work towards some resolution.

* Sharing of motivations to explore relationships with others in similar situations could fulfil the patient's need to find out what the leader was really like.

* The bereavement process - "Part of you does die when you lose your sight"

* Fears of death, dying, in particular suicide, were taboo topics

* This was echoed by direct questioning about how the leaders coped with progression of diabetic complications including amputations

* Sharing fears about suicidal ideas could lead to a richness of experience.

* Verbalising negative and positive feelings could lead to a resolution of shock, panic and anxiety.

* Freedom and confidence gained in 'working things out' with other people could enable members to get back to living as quickly and as normally as possible.

* The support network in the group could allow the human spirit to rise above the experience of blindness.

* 'Group time' could give members opportunities to resolve fears "wrapped up inside" sight, status, despair, work, family and relationships with children, etc.

* Members reflected and shared the leaders functions as good listeners.

* Members were brought out of isolation through discoveries that other people felt exactly the same and were struggling

* Members felt better thus recognising the beginning of a healing process.

* A group could be a starting off point for self-awareness, where feelings were legitimate.

* Experiences gained in living, learning situations enabled people to perceive different ways of thinking about things.

* Members gained through group experiences which could then be used elsewhere.

* The use of directive or non-directive leadership with flexibility was explored.

THE GROUP FOCUSED ON THOUGHTS THAT ALTHOUGH THE HUMAN SPIRIT WAS INDOMITABLE THE UNKNOWN OR KNOWN COST OF SURVIVING WITHOUT ADEQUATE THERAPEUTIC RESPONSE WAS EXPENSIVE.

Management issues:

* Were medical settings the ideal places for counselling?

* What kind of provision could be made for the kind of counselling/training in groups under discussion on October 18th?

* In Hampshire it had been found that social work support was inadequate for the needs of the visually handicapped to sort out problems and talk. An experimental group had been set up for 6 weeks.

* A need was expressed for time, training and professional supervision of people who set up groups.

* The majority of blind patients were told "they were alright" and sent home quickly - the emotional pain unrecognised.

* The need to fill the gap between hospital, social services and home.

* Long term hospital patients received little or no help.

* There was a need to influence colleagues and nurses in medical settings.

* Developmental work was almost non existent.

* The sending of blind people straight from hospitals to institutions or residential homes without adequate preparation was an area for exploration.

* There was a need for training nurses in counselling skills in ophthalmic courses or in service training of nurses.

* In a hospital in the North practical constructive ways of helping out-patients after laser treatment alerted members that blind people had to become problems in order to gain adequate notice for rehabilitation.

* The question was raised about difficulties of changing relationships in families after the blind person had received a great deal of time, care, medical attention or rehabilitation. There were great difficulties where the family had been "left out".

* The disparity between a medical assessment and a functional assessment.

* The research at Kings College Hospital was what had been found from the real experience of patients.

Third Session

Blind and sighted people working together

The session opened with the question - why do we differentiate between speaking to the blind and speaking to each other?
The need for clear communication was expressed with the wish for blind people to be treated as normally as possible.
Amusing interchanges were expressed about the mutuality of difficulties in relationships between blind and sighted people.

Points raised: HOW DO PEOPLE SEE?

* There were wishes expressed that the analysis and assessments of patients should be as 'normal' as possible. Self analysis of limitations of vision could become more realistic in a group of people who communicated freely about vision.

* The growth process in keeping visual memory alive

* The presumption that seeing was confined to physical vision was an illusion.

* The increase of perception - an important way of "seeing" the world around.

* The use of perception in group work with blind patients enabled communication about anxieties and fears to arise.

* The relationship of dreams as a working through process in coping with blindness and associated anxiety was important for regressed patients. (This was illustrated with vignettes about patients whose anxiety dreams changed to 'seeing' or visualising the images of family members, to finding a way through a maze to a centre. Finally there were beautiful dreams about home.)

* The relief felt when sight failed completely was an experience to be built on so that blindness could be coped with and memory trained was described by a totally blind member

* The need for firm leadership - whether directive or non directive - with flexibility.

* The need for abilities to cope with risk taking and uncertainties

* The dangers in group work of feelings getting out of control was a risk and a real fear.

* Issues related to relationships, closeness, distance, the nature of the work; adjustment and compromise were questioned. "Once barriers are broken were problems related to work or were there relationship problems?"

* Assessing situations, physical limitations, based on reality.

* The question of honesty between sighted and blind people "How

well do we know each other?" Why aren't sighted people prepared to confront blind people?" etc. etc.

* The sighted person's inability to tackle the blind persons "persona"

* How blindness affected personalities in different ways

* The dynamics of working things out in safety, through argument and confrontation

* Coping with limitations

The question "How many people were related to problems of blindness in the family - when they were growing up?" was difficult for the group to receive.

* Difficulties in recognition of childhood unresolved emotional problems, or non recognition of their impact was an area for development.

* The realistic difficulties of gaining mutual reasonable relationships if sighted people kept saying "blind people were remarkable"

* The difficulties of blind people having to train themselves in concentrating harder and working longer than sighted colleagues.

* The need to tackle the general assumption that "all blind people were musical, or religious"

* The appreciation of natural talents and mutual acceptance of limitations, in people 'as they are'

* There was some recognition of difficulties in marriage partnerships in adaptation to loss of sight.

The workshop closed with the hope that people would come back and would meet again to explore further.

Mary Todd overheard someone say "We have only just begun."

Memorable words in the dialogue between the leaders when they were discussing fears related to dying, death and in particular suicide "Life is all about dying and death - it is also about birth and joy."

Counselling and Caring for People with Loss or Threatened Loss of Vision

Workshop at King's College Hospital, 18.10.85

Olive Chandler, The United Reformed Church, Kingston-upon-Thames, Surrey

Reflections from a Member of the Group

The Place

The setting of the workshop in both Normanby College and King's College Hospital lent dignity to the proceedings. Within the dignity, there was welcome informality: coffee on arrival, the circle of chairs in the lecture room and buffet lunch. We were blessed with fine weather, merciful for transition between lecture theatre and the Belgrave Room.

Leadership

While joint leadership can present problems, it was on this occasion valuable: the medical 'cover' validated the seminar, as did the generous recognition that the medical colleague had learned from the work that had led up to the workshop; the good colleagueship between the leaders was apparent and reassuring.

Membership

Although the disparity of experience among the members may have presented difficulty to the leaders, there was value in admitting those who expressed interest in coming:

- there was opportunity for each to learn as he or she was able,
- the cross section of experience was useful: local authority and voluntary body; hospital, university, regional council, church;
- the problems experienced were nationwide: Strathclyde, Torquay, Manchester, Hampshire etc.
- It was particularly valuable that blind and sighted people participated together and that there were frank exchanges;
- the part played by the guide dogs should not be underestimated.

Content

The three sessions

Blind People and their Families
Blind People in Medical Settings
Blind and Sighted People Working Together

formed a natural progression, with an interval between each for lunch or tea which loosened discussion so that the last session - the crucial one for the workshop - was the most productive in terms of frankness of comment and opportunity for insight into attitudes and feelings.

Groups or not groups

While one or two members would have welcomed the opportunity to discuss in small groups, the leaders may well have preferred to keep all together, on this first occasion: the leadership of small groups could have presented a problem, those without one of the two leaders feeling deprived. On balance, the decision this time not to break up was probably justified.

Follow-up

More than one member was heard expressing a wish for this. There would need to be a decision as to whether to limit follow-up to members of the same group, by invitation, or whether also to throw open the membership to those interested, catering for a mixed intake. The former would be cosier, the latter might prove further reaching.

Results

Who can tell what modification of attitudes or deepening of insight has taken place - is still taking place - in the minds of those who attended the workshop, or what development of work has happened or is planned in the many centres from which members came? Certainly interest has been further aroused in the work and methods of those leading the King's College Workshop, and this will undoubtedly rub off on many of those present who are involved with people suffering from vision difficulty.

- "Part of you does die when you lose your sight"
- Working through the various stages: of anger - mourning - numbness - sorrow - to possible acceptance
- Different ways of communicating: touch, use of name, intonation of voice...
- "People are not just eyes"

If we had gone home with just that, the day would have been a good day: we went home with much more.

The publication of the research that led to the workshop is still to come; the King's Fund Conference is still to come - two more stages of demonstrating the need for caring and counselling skills to be bonded into the medical skills of those dealing with patients with loss or threatened loss of vision.

Surface Problems Faced by People with Visual Impairment

as seen by a specialist social worker for the blind, Christine Brock, Southwark.

Not being able to read, i.e. dealing with business matters oneself. Talking books give pleasure to former avid book readers, but not everyone is able to concentrate on listening as they did on the printed page. Magazine and newspapers only readers are worst off.

They miss doing household repairs and decorating etc; women miss needlework and interesting knitting. Ordinary housekeeping and domestic activities are part of the pattern of daily life and help to pass the time in a satisfying way. Inability to continue causes enforced idleness and frustration.

Learning to cook in different ways is not easy, especially with gas, which can be dangerous. Meals on wheels are not necessarily the answer. Some people have trouble learning to eat without seeing.

Many people can get to the shops; but seeing the prices is the greatest problem.

Street mobility and travelling are usually seriously curtailed with loss of sight and in many areas no mobility training is available. Gradually confidence wanes and people become used to a restricted life and less willing to learn independence.

Those who led active social "out and about" lives, particularly in retirement, are sadly affected. Friends and family may give good support, but the loss of independence is deeply frustrating.

Sometimes a partner cannot accept the limitations of a visually impaired person, and the new responsibilities and consideration needed, and the relationship deteriorates. More often, the partner can become over protective and helpful, limiting the capacity to learn to adapt.

Sometimes parents cannot accept that their child is disabled and do not seek the appropriate schooling etc.

Even following excellent training, young blind people can be a long time finding employment.

SURFACE PROBLEMS ARISING FROM SIGHT LOSS (Patients Disclosures)	ELEMENTS INVOLVED IN HELPING THE PATIENT
Fear for the future	Encouraging hope
Will I be in total darkness?	Teaching other ways to do things
Will I ever work again?	Persuading that a white stick is not a stigma
How will I cope with cooking, shopping, ironing etc. getting out and about, making phone calls?	- but can open doors - introduce ideas
Will he/she still love me?	- leave till asked
What will people think?	
I don't want pity	Getting past false hopes of cure to acceptance.
I mustn't make a fool of myself i.e. tripping, falling over, spilling things.	Identifying with grief over loss.
Being blind is being a second class citizen	Helping to heal pain.
What have I done to deserve this?	
I can't read or write anymore, or knit or sew.	
I've lost my independence	
I've lost my privacy	
I'm no use to anybody now	
I could't use a white stick	
People are so sympathetic - I need encouragement	
Nobody has explained exactly what's wrong	
I thought I was certified when I was registered blind.	
How can I meet boys/girls now?	
How can I make friends?	
I keep bumping into things	
I keep losing things	

In later life, there may be a long wait for rehabilitation, assessment and training, and then employment problems.

There is an enormous need for educating the public in understanding visual handicaps. The "does he take sugar?" attitude is widely prevalent. Most younger blind people have "horror" stories of public stupidity, e.g. blind man with white stick waits at street crossing. Motorist stops and flashes lights to indicate "cross now", then complains loudly when blind man does not cross!

Awareness of emotional anxieties and traumas experienced at onset of visual loss is just as necessary. Understanding visual limitations of in-patients should be part of every nurse, doctor and ward orderly staffs' training . Counselling and liaison with Social Services help are important as early as possible.

Elderly people whose sight has deteriorated slowly have usually learned to adapt and manage their lives.

Children and young people who have the appropriate schooling and training are also able to lead active lives. Their difficulties are more likely to be in forming close relationships with their sighted peers. "Boy meets girl" is not easy when you can't see the prospects available.

It is the people whose sight goes fairly quickly, who become unemployed, who cannot contribute to their family lives as before and who have to face a future totally different from what they might have expected, who have the most painful adjustments to make.

Blindness is always a very hard disability to accept, is often denied for sometime, and is in effect a bereavement process involving anger, resentment, despair and many questions. Tactless sympathy from well meaning people can be humiliating.

Imaginative common sense can be the most helpful provision from involved persons.

MY VIEW OF UNDERLYING PROBLEMS CONTRIBUTING TO SUICIDAL RISKS IN PATIENTS WITH LOSS OF VISION/BLINDNESS

Misunderstanding or denial or lack of understanding or empathy between patients and clinicians because of non-recognition of psychological effects of blindness or loss of vision. The failure to recognise or respond to the psychological effects of blindness or loss of vision increases the patient's isolation and therefore the suicidal risk.

Denial of the effects of loss in the patient and immediate family due to unresolved losses in the present or past history of blindness in the family.

Hidden depression (dreams of catastrophe, falls, destruction, self-destruction).

Depression - self depreciation, tension, agitation, anxiety.

Continuous complaints of physical symptoms.

Fear of loss of control, hurting others due to unresolved feelings of anger about loss of vision.

Previous suicidal attempts or suicidal ideas.

History of broken home before the age of fifteen or loss of a parent in childhood or adolescence.

Serious physical illness in addition to blindness e.g. loss of limbs, diabetic complications, neuropathy.

Personality Problems

a) Hysterical personalities who react to frustration with physical symptoms - transient mental states, e.g. memory loss or insatiable urge for love and attention.

b) Neurotic personalities - originating from broken home, early inhibition, discouragement, defective ego development, traumatic childhood experiences.

c) Sado/Masochistic personalities in which self damaging tendencies affect individuals development.

d) Anti-social psychopaths.

Marital, sexual problems, illness in family, loss/death of partner or family occurring around the time of loss of vision.

Anxiety due to financial insecurity due to threat of loss of job, unemployment, finance due to blindness.

Fear of dying as a diabetic with disintegration of body and nervous system - where "no one wants to know".

Mental illness

a) Schizophrenics at risk where there are delusions, hallucinations where there are inner voices heard.

b) Psychotics -

c) Borderline personalities

d) Alcoholics

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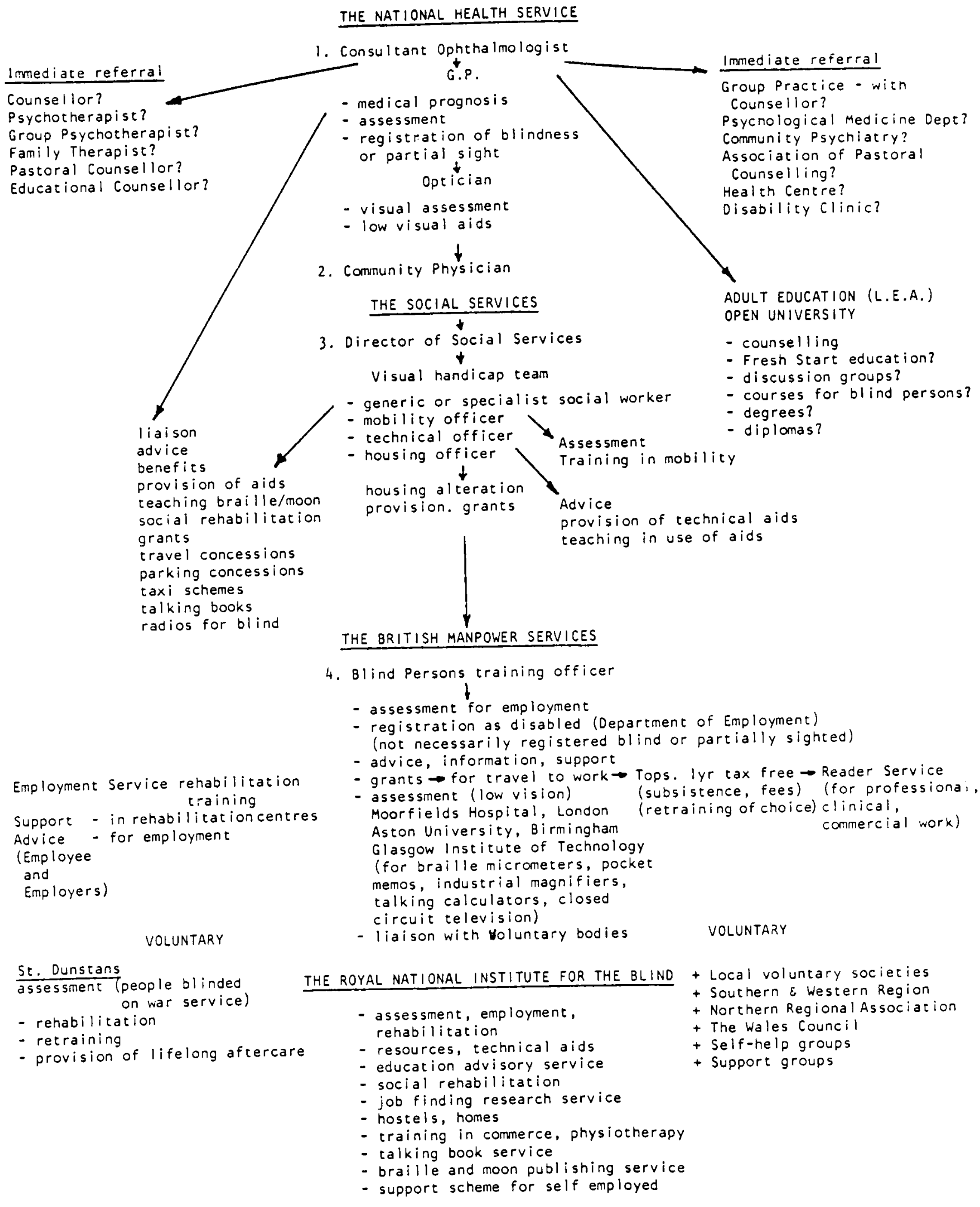
A GUIDE FOR G.P'S., HEALTH VISITORS, NURSES, SOCIAL WORKERS, PATIENTS, RELATIVES OR FRIENDS CONCERNED ABOUT LOSS OR THREATENED LOSS OF VISION

PATHWAYS INTO REHABILITATION - WHICH WAY?



THE NATIONAL HEALTH SERVICE

1. Consultant Ophthalmologist
G.P.
- medical prognosis
- assessment
- registration of blindness or partial sight

Optician
- visual assessment
- low visual aids

Immediate referral

Counsellor?
Psychotherapist?
Group Psychotherapist?
Family Therapist?
Pastoral Counsellor?
Educational Counsellor?

Immediate referral

Group Practice - with Counsellor?
Psycnological Medicine Dept?
Community Psychiatry?
Association of Pastoral Counselling?
Health Centre?
Disability Clinic?

2. Community Physician

THE SOCIAL SERVICES

3. Director of Social Services
Visual handicap team
- generic or specialist social worker
- mobility officer
- technical officer
- housing officer

housing alteration
provision. grants

Assessment
Training in mobility

Advice
provision of technical aids
teaching in use of aids

liaison
advice
benefits
provision of aids
teaching braille/moon
social rehabilitation
grants
travel concessions
parking concessions
taxi schemes
talking books
radios for blind

ADULT EDUCATION (L.E.A.)
OPEN UNIVERSITY
- counselling
- Fresh Start education?
- discussion groups?
- courses for blind persons?
- degrees?
- diplomas?

THE BRITISH MANPOWER SERVICES

4. Blind Persons training officer
- assessment for employment
- registration as disabled (Department of Employment) (not necessarily registered blind or partially sighted)
- advice, information, support
- grants → for travel to work → Tops. 1yr tax free → Reader Service
- assessment (low vision)
  Moorfields Hospital, London
  Aston University, Birmingham
  Glasgow Institute of Technology
  (for braille micrometers, pocket memos, industrial magnifiers, talking calculators, closed circuit television)
- liaison with voluntary bodies

(subsistence, fees)
(retraining of choice)

(for professional, clinical, commercial work)

Employment Service rehabilitation training
Support - in rehabilitation centres
Advice - for employment
(Employee and Employers)

VOLUNTARY

St. Dunstans
assessment (people blinded on war service)
- rehabilitation
- retraining
- provision of lifelong aftercare

THE ROYAL NATIONAL INSTITUTE FOR THE BLIND

- assessment, employment, rehabilitation
- resources, technical aids
- education advisory service
- social rehabilitation
- job finding research service
- hostels, homes
- training in commerce, physiotherapy
- talking book service
- braille and moon publishing service
- support scheme for self employed

VOLUNTARY

+ Local voluntary societies
+ Southern & Western Region
+ Northern Regional Association
+ The Wales Council
+ Self-help groups
+ Support groups

This booklet has been compiled in order to clarify misunderstandings about visual loss and blindness.

It is an attempt to answer patients' questions with some ideas and suggestions of how to cope with decreasing vision and find a way through the puzzling jungle of 'rehabilitation'.

It is hoped that choices made will lead to acceptance of visual loss, restoration of self-esteem and enhancement of the quality of life.

What shall I do? I think that I am losing my sight.	Go to the G.P. for a routine eye test or examination. He can refer you to a qualified Ophthalmic Optician, the General Ophthalmic Service or the Hospital Service. Take someone with you. If there is sudden pain or sudden loss of vision DO NOT DELAY. TREATMENT MAY BE REQUIRED URGENTLY. Go to a Casualty Department as quickly as possible. Ask to see an Ophthalmologist - be persistent, don't give up.
What is usually the role of the Ophthalmologist?	Usually the role of the Ophthalmologist is fourfold: Where possible to improve vision, to prevent further deterioration, to maximise use of the remaining vision, and where indicated assess and register the patient as partially sighted or blind. Within this is also a counselling role of treating the whole person "not just eyes".
What is the nature of visual handicap?	There is loss of central vision, loss of peripheral vision or a combination of both. The macular area of the retina is responsible for fine detail needed for reading or detailed visual work. Visual acuity is a measure of the function of this area. Colour vision is also a function of the central retina.

	The outer peripheral vision is essential for full awareness of the immediate environment and for navigation purposes. Dark adaptation is a function of the peripheral retina. This is essential for night vision.
What are the common causes of blindness?	Diabetes, glaucoma and over the age of 65 years, senile macular degeneration.
What is diabetic retinopathy?	This is now one of the commonest causes of blindness affecting many diabetics who have been insulin dependent usually for 10-20 years. Vision can be affected in two ways, either through macular disease with inability to read small print; or from the development of new blood vessels on the retina (back of the eye). Bleeding from these new vessels can lead to retinal detatchment and blindness. The prognosis is very difficuly to predict.
Can low blood sugar levels affect sight?	Yes. In some insulin dependent diabetics the vision may change from hour to hour due to low blood sugar levels affecting the fluid in the eyes.

How can diabetic retinopathy be treated?	New treatments have been developed using laser light beams. These can accurately seal leaking blood vessels on the retina. There is also a new operation called vitrectomy which can clear vitreous haemorrhages which obscure vision.
Will the treatment alter my sight?	The treatment is given to prevent further damage. The condition of the eye may cause night blindness and difficulty in adjusting to light and darkness. It is difficult to generalise. It is advisable to ask your ophthalmologist for his opinion.
What is glaucoma?	Glaucoma is an eye disorder in which the eyeball becomes harder. This is because watery fluid in the eye behind the iris does not drain freely. The pressure in the eye rises. This may damage the optic nerve head.
Are there different types of glaucoma?	Yes. There is acute glaucoma when suddenly the eye gets very painful and red, with a hazy surface and misty vision. This needs urgent hospital treatment. There is chronic glaucoma slowly developing where the eye gets harder. The blood supply is cut off to the optic nerve, causing blank patches in the field of vision. There is occasionally low tension glaucoma, or inflammation or other trouble in the eye

	which blocks the normal flow of fluids through the eye (secondary glaucoma).
Can glaucoma be treated successfully?	Yes. It can be controlled. Further loss of vision is prevented in the majority of patients. Treatment is by pills, eye drops or surgery. This is to lower the pressure in the eye and drain the fluid.
I do not understand the term 'cataract'.	'Cataract' refers to any opacity occurring within the normally transparent lens. Cataracts can occur in the newborn infants, juveniles and adults but much more commonly in the elderly.
What are the surgical procedures?	The ophthalmic surgeon may recommend removal of the cataract and then the use of high powered spectacles or contact lens. a new surgical procedure called Intra-Ocular Inplant is now being performed. The lens that is removed from the eye is replaced at the same time by a small plastic lens inside the eye. This modern practice has eliminated the optical distortion caused by thick cataract spectacles and has allowed earlier treatment of cataracts.
Can I have other 'eye troubles' as well as cataracts?	Yes. Many patients registered as blind with cataracts also have co-existing ocular

	disease such as senile macular degeneration or chronic glaucoma. Don't however become a hypocondriac. Hold on to the sight you have and be positive. "Hope springs eternal".
What is Senile Macular Degeneration?	Overall, it is the commonest cause of blindness among persons over the age of 65 years. There is distortion of the central vision, progressing eventually to the development of a dense central scotoma and a fall of visual acuity to less than 6/60. The peripheral field of vision is maintained.
Is there any treatment?	For the majority the condition is untreatable. A small number of patients may benefit from laser treatment.
Are other causes of visual loss due to degenerative disease?	Other less common causes of visual loss are degenerative myopia, where there may be atrophy of the choroid and retina leading to a disabling loss of vision. Also included is retinitus pigmentosa - an inherited condition causing night blindness, tunnel vision and neurological disease. Cerebro vascular accidents may cause extensive visual field loss. In multiple sclerosis optic atrophy can result in progressive loss of visual acuity.

Are additional handicaps general in those people with visual loss?	Sixty per cent of those registered blind have at least one additional handicap. Physical handicap, deafness and diabetes cause particular problems.

COMMUNICATION

No one mentions the word blindness. Is it advisable to mention this word?	The word has emotional connotations. For many people it is understood to mean total loss of vision. Only a minority of registered blind people have total visual loss or have no perception of light. 85% of people registered blind in England and Wales have some useful vision.
You haven't answered my question.	No. This is because the word has painful associations because of insensitive ways it can be used. A barrier of fear may be erected when the word 'blind' is never mentioned. The gambit "How much can you see?" can lead to open ended conversation Feelings of emotional pain, numbness, anger, fear or sadness can be explored and clarified. The word 'blind' can then be used more freely.
My ophthalmologist says "I am not going blind." I have no vision in one eye and the other eye is deteriorating	Ask your diabetic physician or ophthalmologist to explain in your language precisely what he means, so that you can prepare for the future.

because of diabetic retinopathy. I am anxious about the future. What shall I do?	Referral to a counsellor may help.
That's all very well, I don't feel I can cope.	Find a person with whom you can talk. Find time to clarify and explore problems, difficulties or changes in life style.
I can't stop crying.	If you feel depressed have a talk with your General Practitioner. If he says "What can I do?" it may be necessary to seek professional help from a qualified counsellor, therapist or psychiatrist. Don't be afraid to ask. Blindness may be the 'presenting' problem. Underneath there may be deeper problems associated with loss of security or isolation.
I have diabetic retinopathy. Should I lift, bend, stoop, blow my top, get excited, upset or have sexual intercourse around the time I am having laser treatment?	We are all human. Some people suffer from stress and tension to a greater degree than others. Diabetics are sometimes more psychologically brittle than other people due to fears of diabetic complications, loss of limbs, etc. A good maxim is to keep calm, don't panic, keep going slowly. Express feelings little by little for a time. Ask your G.P. or ophthalmologist for his opinion. It may be necessary to restrict physical activity for a time, depending on the delicate state of the eyes.

I am frightened of doctors, hospitals and authority figures.	Share your misgivings. Be open about your feelings, thoughts and fears. Medical or psychiatric treatment can be supportive and caring in life crises. If you have severe physical disabilities plus loss of vision ask your G.P. Community Health Council whether there are Rehabilitation Clinics in your area.
How can the family help?	Gather the family together and talk it over. Arrange the family screening, especially if family members seem to be getting similar symptoms as yourself.
Should I drive to the hospital when an appointment is made for laser treatment or for fluoroscein photography?	It is advisable not to drive at this time.
I have to travel a long distance to see my specialist. My family get anxious about me travelling alone, especially when I am recovering from hospital treatment. Have you any practical suggestions for me?	If possible think ahead and plan your hospital visit carefully. Some hospitals have a car service for people who can neither see nor walk. The British Red Cross or Local Councils of Voluntary Social Service will provide escorts for long journeys. Ask the Secretary of the League of Friends of the hospital to co-operate. If you travel by British Rail, contact the Manager of you local station to put you on the train and arrange for an

escort at the other end. Ask whether there is a tactile map available. When you arrive at the hospital ring your family so that they know you have arrived safely.

REGISTRATION ONWARDS

What is the definition of blindness for Registration purposes?	In the U.K. a person is eligible for registration 'if he cannot perform the work for which sight is essential'. Definitions vary in degree of loss from total lack of vision to much reduced visual fields. Registration is voluntary and can entitle you for central or local Government services and for the support of voluntary societies.
If I become severely blind where can I get special information?	Dial 100 and ask for the Department of Health and Social Security 'Freephone'. Ask for the Severe Disability Information leaflet. Think about retraining for employment. Ring the Social Services. Press for the services of a technical or mobility officer. Ask your G.P. if there is a Disability Rehabilitation Clinic in a Hospital or Community Health area. Ring the R.N.I.B. for information. Be persistent. Don't give up. Ask your friends to help and you will help them.

Can you explain precisely what 'registration' means. I was told I would be 'certified!'	Each Borough county council, London Borough or Metropolitan district keeps a register of people who are registered blind by a District or Hospital Ophthalmologist. Friends, relatives, social workers, home helps, etc., can put in a request for registration with the permission of the person concerned. For the blind or partially sighted person registration is voluntary.
What is the usual procedure?	The Ophthalmologist examines the person. He fills in a form (B.D8). If he considers it necessary he will recommend training, or rehabilitation. (In King's College Hospital he can refer a person with threatened or loss of vision immediately for group, individual or family counselling or therapy. This initiates action which is the first stage of rehabilitation. It has proved valuable. Patients are encouraged to be involved in the relief of suffering and the enhancement of life).
What is the next move?	The B.D8 form is sent to the Community Physician. Details are then sent to the appropriate Social Services Department. In King's College Hospital the Consultant Ophthalmologist will also write requesting appropriate services. A letter is also sent to the G.P.

Can I register as disabled with the D.H.S.S. if I am not registered blind?	Yes, if your vision is deteriorating you can be registered disabled. You will need to back your application with a letter from your G.P. or Ophthalmologist. Even if you are not registered blind this may be useful for a time. Otherwise paint your own walking stick! Keep going out with a friend. Co-operate with your friends, family, colleagues but don't be swamped with kindness.
Where else can I seek or give help?	There are many avenues open to you. Here are a few ideas:- Listen to the BBC 'In Touch' programme, Radio 4, Tuesday at 9.00 p.m. Send a stamped addressed envelope to the BBC - Room 816, Portland Place for the 'In Touch' bulletin. Tel. 01-580 4444. Also 'Guideline' Radio London every other Saturday 6.00 - 6.30 p.m. Contact Community Care ventures or Ecumenical Centres.
Isn't there something more practical I can do? I am trying to cope with partial sight.	Yes. There are Voluntary Societies who offer practical help. The Partially Sighted Society offers advice and low visual aids centre, and are organising developmental work in 9 areas in England and Wales and in Greater London. Tel. 03317 3036. The Disabled Living Foundation employ an adviser and part-time optician. They have

	the 'In Touch' demonstration kitchen in their premises in Kensington High Street, London. Tel. 01-602 2491.
What is the best way to apply for a grant for retraining?	The Manpower Services Commission employ Disablement Rehabilitation Officers who will interview you. Enlist their help and advice and think through new possibilities of retraining with them. The Department of Education and Science also offer grants to mature students. Think carefully before giving up any employment to retrain. You may be wiser to continue your present work but use some leisure time to train for alternative employment. The Manpower Services Commission give grants for retraining for up to one year only.
How long do I wait for help from the local authority workers?	This varies enormously from one part of the country to another. In some areas there is little or no help available. In many Social Services Departments visual loss is given a low priority. There is, however, a growing awareness of problems. There may be a social worker attached to an eye clinic.

There is little or no service in my area. What shall I do? I am frightened to go out.	Ring the R.N.I.B. Information Service for help. They can supply a white cane. State your registration number, height and address, they will post one to you. Tel. 01-388 1266. The Disability Alliance will offer advice on financial matters. Tel. 01-402 7026. There are Low Visual Aids Clinics attached to some Ophthalmic Hospital Services. There is the Talking Newspaper Service, which can keep you in touch with local news and events. In some areas this service comes with friendship in the form of a personal introductory service. Tel. 01-602 2491.
Can I go into Further Education?	Approach your local Adult Education Service. There may be a Student Adviser of Counselling Service. Consider widening your horizons with the Open University where there are specialist Open University Counsellors with special responsibilities for Disabled Students. Tel. 0908 74066. Contact the Educational Centres Association for their 'Fresh Start' courses or schemes or grants. Tel. 01-251 4158. It is impossible to list all possible avenues of help in this paper. Listen and explore new ways, changes and leisure. Everyone can come together to share resources.

A full comprehensive address list may be found at the back of the BBC 'In Touch' handbook, BBC Publications, PO Box 234, London, SE1 3TH.

Here are a few useful addresses: -

The Disabled Living Foundation

346 Kensington High Street, London W14 8SS. Tel. 01 602 2491.

Age Concern

Bernard Sunley House, 60 Pitcairn Road, Mitcham, Surrey CR4 3LL. Tel. 640 5431.

Association of Blind Chartered Physiotherapists

206 Great Portland Street, London W1N 6AA. Tel. 01 388 1266.

British Diabetic Association

10 Queen Anne Street, London W1M OBD. Tel. 01 323 1531.

Blind Mobility Research Unit

Department of Psychology, University of Nottingham, University Park,
Nottingham NG7 2RD. Tel. 0602 56101 ext. 3187.

British Red Cross

9 Grosvernor Crescent, London SW1X 7EJ. Tel. 01 235 5454.

British Talking Book Service for the Blind

Mount Pleasant, Alperton, Wembley, Middlesex HAO 1RR. Tel 01 903 6666.

British Wireless for the Blind Fund

226 Great Portland Street, London W1N 6AA. Tel 01 388 1266.

Churches Council for Health & Healing.

St Marylebone Church, Marylebone Road, London W.1. Tel 01 486 9644.

Counsel and Care for the Elderly

131 Middlesex Street, London E.1. Tel 01 621 1624.

Useful addresses continued-

Department of Health and Social Security Leaflets Unit

P.O. Box 21, Stanmore, Middlesex HA7 1AY.

Education Centres Association

Chequer Institute, Chequer Street, London E.C.1.   Tel. 01 251 4158.

Disability Alliance

21 Star Street, London W2 1QB.   Tel. 01 402 7026.

Express Reading Service

79 High Street, Tarporley, Cheshire CW6 0AB

Guide Dogs for the Blind Association

Alexandra House, 9/11 Park Street, Windsor, Berkshire S14 1JR.   Tel. 075 35 55711.

Hypoguard Ltd. (for special syringes)

Dock Lane, Woodbridge, Suffolk TP12 1PE.   Tel. 03943 7333.

International Glaucoma Association

King's College Hospital, Denmark Hill, London SE5 9RS. Tel.01 274 6222.

London Association for the Blind

14-16 Verney Road, London SE16.   Tel. 01 732 8771

Multiple Sclerosis Society.

286 Munster Road, London SW6 6AP.   Tel. 01 381 4022.

Patients Rights. A guide for N.H.S. patients and doctors.

Her Majesty's Stationery Office, 49 High Holborn, London WC1V 6HB.   Tel. 01 211 5656.

Partially Sighted Society

Secretariat Office, Breaston, Derby.   Tel. 03317 3036.

Royal National Institute for the Blind

224/6/8 Great Portland Street, London W1N 6AA.   Tel. 01 388 1266.

The Open University

Walton Hall, Walton, Milton Keynes.   Tel. 0908 74066.

The Talking Newspaper Association of the United Kingdom

68a High Street, Heathfield, East Sussex TN21 8JB.   Tel. 04352 6102

'Insight' Supplement

This booklet attempts to answer some questions about visual loss - with ideas and suggestions for ways in which loss or threatened loss of vision can be coped with.

The blindness may be the result of loss of central vision, peripheral vision or a combination of both. Less commonly, it may be due to disorders of ocular notility.

In the central vision - the macular area of the retina is responsible for the fine discriminating vision needed for detail or reading. Colour vision is predominantly a function of the central retina.

The outer area of the visual field - peripheral vision is essential for awareness of the immediate environment, particularly for navigation.

Dark adaptation or night vision is a function of the peripheral retina.

In disorders of ocular notility, paralytic squints, nystagmus and gaze palsies give rise to varying degrees of visual disability.

Causes of blindness
macular degeneration

- the commonest cause of blindness over the age of 65 years.
- distortion of central vision is accompanied by progressive loss of visual acuity. Vision becomes dense.
- the final result is less than $\frac{6}{60}$ and the disease is bilateral.
- A few persons benefit from laser coagulation. For the majority the condition is untreatable

Chronic glaucoma - Approximately 13% of persons registered blind have chronic glaucoma. There is a gradual contraction of the visual field - with preservation of the central vision until the later stages.

- Lowering the intra ocular pressure by drugs, surgery or surgical drainage can arrest or slow down loss of vision.

Diabetic retinopathy - This is the commonest cause of blindness in young adults.

- Retinopathy is a common complication of the disease. It may affect vision in two ways; the macular can be damaged by haemorrages, exudates or vedema - with gradual loss of visual acuity. The proliferation of new blood vessels from the optic disc and surface of the retina, bleed; causing repeated vitreous haemorrages.
- Laser photocoagulation of the retina and micro-surgical techniques - for repairing the damaged retina have greatly improved the visual prognosis of diabetics with eye disease.
- Vitrecomy - can help to clear vitreous haemorrages.

Cataract - This is the common cause of visual disability in the elderly population.

- With a few exceptions it can be successfully treated - even in the very old and infirm. Optical distortion caused by thick cataract spectacles

		can be overcome by the widespread practice of intra - ocular implantation.
Retinitus pigmentosa	-	This familiar disease causes progressive contraction of the visual field - leading to tunnel vision and night blindness. There is no effective treatment.
High myopia	-	This is a degenerative condition.
	-	The choroid and retina atrophy - leading to visual loss particularly in the central area.
Cerebra vascular Accidents		Homonymous visual field defects result from involvement of the optic readiations or visual cortex.
	-	Gaze palsies result from the involvement of the higher centres controlling ocular movement.
Multiple sclerosis	-	Repeated attacks of optic neuritus give rise to optic atrophy and progressive loss of visual acuity.
	-	Nystagmus further limits the vision.
Blindness	-	Very few persons registered blind are totally without sight - unable to differentiate between darkness and light.
	-	The definition of blindness is deliberately vague - for the purpose of registration in the UK. "So blind .....? If unable to perform any work for which eyesight is essential".

Partial sight - There is no statutory definition of partial sight.

- For registration purposes more with visual acuity between $\frac{3}{60}$ are eligible. Visual loss in one eye does not constitute partial sight.

Acknowledgement

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