
The Patient Support Service at Gartnavel Hospital Eye Department

An Evaluation of the First Year

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An Evaluation of the First Year.**

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Foreword

This report describes the process of setting up a patient support service in the eye department of Gartnavel Hospital in Glasgow. This pioneering service is the first of its kind in a Scottish hospital.

Initially funded for one year, the aim was to pilot a new service and evaluate the impact on patients and staff. The report provides a detailed analysis of the first year of the service in terms of both quantitative and qualitative indicators. This analysis shows an overwhelmingly positive response to the service, to the extent that it is now considered an essential and integral part of the eye department. The service has far exceeded all expectations, further funding has been awarded and the service is now well in to its second year.

The service provides an opportunity for people to talk about how their sight loss is affecting their quality of life. A fundamental principle of the service is a patient centred approach, in which the support is tailored to the needs of each visually impaired person. People talk about a wide range of issues but most often, it is the social and functional aspects of visual impairment which are causing them difficulties.

The report records the challenges and opportunities of establishing and integrating a social support service into a medical world. The message of the report is that it is a very empowering experience for all those who have been involved, patients, hospital staff, social services staff and Visibility.

Working in partnership, Greater Glasgow NHS Health Board and Visibility have established this new service. However credit must also go to the staff within the eye department at Gartnavel who have embraced the service wholeheartedly. Their support has helped to create a quality service, which is highly regarded and in constant demand.

The challenge for the future is to manage the growing demand, maintain the levels of excellence and yet continue to develop to meet the needs of visually impaired people.

Summary

The report identifies several key factors in the successful development of the patient support service. It also provides findings and statistics on who is using the project, and why. The key points are: -

- Involvement of key hospital staff in planning and implementation is critical.
- An understanding of the social and functional aspects of visual impairment and how these need to be integrated into a medical world is important
- Feedback to staff was crucial to gain professional credibility.
- A full time post covering all clinics provides a consistent presence, and provides opportunity for immediate access.
- Listening to the patient and tailoring the support to their needs is a fundamental principle of the service.
- A dedicated room where people can discuss concerns in privacy is important.
- Patients who are experiencing major difficulties and urgently need help are now “fast tracked” into community based support.
- Both quantitative and qualitative indicators demonstrate high usage and great satisfaction with the service from both patients and staff.
- Hospital staff now have a better understanding of the functional and emotional issues facing patients and now consider the service an essential part of the care provision.
- Average referral rate is around 60 people per month, with just over half receiving support by telephone.
- The typical person referred is female, over seventy years old, living alone, struggling with day-to-day issues, and unaware of any support services.
- Over 75% of patients required practical help and advice and around 60% of patients were in need of emotional support.
- The main issues for patients were around fear of the future, loss of skills, loss of confidence and loss of independence.
- Nearly 65% of people were given details of how to contact their local social services department.
- People appreciated that someone had time to listen, someone who understood their needs and who could provide information, at a time when they needed it.

1. Introduction

Receiving the news that a sight problem cannot be treated or cured is devastating, even if the person has been living with deteriorating vision over a period of time. Confronted with the realisation that their sight will not improve, and may get worse, people need to know what help is available. They want to talk about what their sight loss means to them, and how their needs might be met. However, across the country, there is a wide variation in the services and support that is available to people with a visual impairment.

It is estimated that about two million people in the UK have a severe visual impairment. Many of these people are elderly, with 90% of blind and partially sighted people being aged 60 and over. Over the next thirty years, approximately 40% of the UK population will be over 60 and so the problems associated with visual impairment will increase. Despite these changing demographics and the numerous reports, visual impairment does not appear to be a priority for the statutory agencies.⁴

In the Greater Glasgow NHS Board area, progress is being made towards addressing the needs of visually impaired people. The Health Board has been visionary in its partnership funding of several projects with Visibility (formerly Glasgow and West of Scotland Society for the Blind) to identify and develop services for visually impaired people. In the first of these projects, a wide range of professionals and service users were asked to identify the gaps and opportunities in service provision. From this initial work, several recommendations arose. The most universal and pressing need that was articulated by all, was for access to emotional support, information and advice, especially at the point of diagnosis of serious sight loss. Greater Glasgow NHS Board and Visibility responded to this by piloting a patient support service in the busiest eye department in the city, at Gartnavel Hospital. This would be the first of its kind in Scotland, a service dedicated to providing emotional support and advice within the eye clinic setting.

From the outset of the service, the aim was to establish a professional service, which listened to patient's concerns, complemented the medical services and provided a bridge into social and functional support for people. This is exactly what this

post has achieved and with great success. It is a holistic, patient centred service that provides immediate contact not only for the person diagnosed with serious sight loss but also for the families, carers, and associated hospital and community based professionals.

As the report will demonstrate, the service is regarded very highly, by both staff and patients and is now seen as an essential part of the eye department. The project is also gaining a national profile as a model of good practice. In particular, it demonstrates the value of a Health Board, a voluntary organisation, hospital staff, and social services staff, all working in partnership to improve the overall service for patients.

Establishing a social support post and integrating it into a medical setting has not been without its challenges. The aim of this report is to describe some of these challenges. The report will describe the background to the service, the operational elements, and feedback from professionals and service users. It examines how the project has influenced the patient's journey from the medical world of sight loss to the social world of living with a visual impairment. Finally, the report assesses the impact of the project on the work practices of hospital staff.

2. National Context

Many national reports highlight the difficulties experienced by visually impaired people, such as inadequate services and poor support for patients. However there are two reports in particular, which informed the development of this new patient support service.

2.1 Patients Talking

In 2000, "Patients Talking"¹ was published, which describes patients' experiences of attending eye clinics. This report was followed by a larger more in depth study, "Patient's Talking 2"². Both studies identify the need for improvements in terms of information, counselling, support and follow up. It states that:-

"the one outstanding finding of this study is the lack of initial counselling and support for people facing serious and

permanent sight loss. Seventy percent (70%) wanted someone to talk to about their concerns but only nineteen percent (19%) had been offered the opportunity”

2.2 Closing the Gap

This report³ identified the gaps in provision between the health service, social services and the voluntary sector. It discussed the gaps within services, between services and highlights the need to bridge these gaps. It states that: -

“early intervention and recognition of need, rather than registration status is the best trigger for action The sequence and phasing of support is increasingly being recognised as of real importance in people’s successful adjustment to losing their sight”

3. Local Context

In 2001-2002, Visibility (formerly Glasgow and West of Scotland Society for the Blind) was commissioned by Greater Glasgow NHS Board to undertake local research to examine service provision and develop services to meet needs.

3.1 Patient’s Journey

A key part of this work was to map the information using the concept of a “patient’s journey “ through the services. Appendix 7 demonstrates the key stages within this journey. The notion of a journey assumes that the person enters a system, but many do not as they believe that their deteriorating sight is due to old age and that there is no help available. This is often the view of GP’s who see no value in referral into the hospital sector, and are unaware of local sources of support. For these patients, there is no journey. There are in fact several points at which people have no contact or further contact with services and no clear route to accessing support. As a result, they are lost to the system and they do not get advice, equipment and benefits which might make everyday living with a visual impairment easier. It is also the case that even if a person is journeying through services, there are long waiting times when their way of life may already be compromised by failing sight.

For many people with a visual impairment, help and support is too little, too late.

3.2 Registration as Gateway or Gatekeeper?

Registration is the process whereby the consultant assesses whether a person's sight has deteriorated to one of two levels, defined as partially sighted or blind. It is important to note that it can also be regarded as the formal gateway to social and functional support for sight loss. However, it is also true to say that the process is not well understood, nor is it applied in a consistent manner.

If the patient agrees to registration and is eligible, it will trigger an assessment of needs by their local authority social work services. This assessment should open the door to aids and equipment provision, mobility training, employment advice, possibly welfare benefits and other concessions as appropriate. Access to these can make a substantial difference to quality of life.

Registration is voluntary for the patient, but the clinical decision to register is the sole responsibility of the eye consultant. This means the situation can arise where a person can be clinically eligible for registration but chooses not to be registered. This can be for a variety of reasons, but is often because they do not wish to be labelled as "blind". Additionally some patients may reject the idea of social work involvement and therefore reject registration. Alternatively, there are some patients with significant sight difficulties, but the clinical definition of their visual impairment may not "fit" with the registration criteria so they are ineligible.

Often medical/ nursing staff are not fully conversant with the benefits of registration and this means they may not be able to fully discuss the options with patients. It is also true to say that some staff view registration negatively, and therefore are reluctant to register people.

In theory, visually impaired people do not need to be registered to access aids, equipment and support, but in reality registration is often used as a way of prioritising scant, under resourced services.

Many people remain on a "patient's journey" over several years and may never be registered, and yet can experience similar

problems with day to day life as those who are registered. It is these inconsistencies and anomalies of the registration process that make a difficult situation, even more difficult and confusing.

3.3 No More Can Be Done

It is recognised both locally and nationally, that one of the most difficult points in the patient's journey is the point of diagnosis for which there is no treatment. At this stage, patients are often told "*no more can be done*". Whilst this is meant in the medical sense, it is interpreted as "*nothing and nobody can help you*". Many people leave the hospital bewildered, anxious and with no idea of what to do. The situation is compounded by the fact they have been told that they do not need further appointments at the hospital, so they feel they cannot come back to ask their questions.

Whilst it may be the case that medically no more can be done, there is much that can be done to support the social and functional aspects of living with a visual impairment. However that is not the message that the patient hears, nor are there obvious sources of help and support. What is needed at this point is appropriate information and advice to support the transition from the medical world of untreatable sight loss, to the social world of living with a visual impairment.

3.4 Proposed Development

It was clear from the local research that visually impaired people wanted to talk to someone about the implications of this news for them, their families and their way of life. Equally the hospital professionals were aware of this need, but were unable to give support. In many cases, they admitted that they knew very little about what help might be available and had little time to find out and pass the information to patients. Social services professionals acknowledged long waiting times of up to a year before people received support from them.

Based on these findings, a recommendation was made that a new service to provide emotional support within the eye department of Gartnavel Hospital was piloted.

Visibility submitted a proposal to Greater Glasgow NHS Board to set up and evaluate the impact of such a service. The proposal defined the parameters of the service and estimated the costs to be around £30,000. To facilitate this development, the original researcher post was retained and extended to include implementation and coordination of the new service. In essence, this has meant that there have been two workers on the project, one directly seeing patients and one with a coordination, management, monitoring and evaluation role. This team approach has contributed significantly to the amount the project has been able to achieve, evidence and report in a relatively short space of time.

4. Creating A New Service

The objectives of the new service were :-

- to provide emotional support and time to patients attending ophthalmology clinics
- to listen to the concerns expressed by patients, families and carers
- to supply information to patients families and carers
- to work with patients to help them identify their needs
- to be a continuing contact for patients
- to create a bridge between hospital and community based services
- to provide support and information to clinical staff
- to establish good working relationships with clinical staff
- to identify patients at risk and refer to appropriate agencies

In the development stages, comments were invited about the skills and background experience that were needed to achieve these objectives. Interestingly, medical and nursing staff initially felt that the post holder should have a clinical background, while social services staff felt that the post holder should have a social work background. The common theme was the need for boundaries and that the post holder should not encroach on medical, nursing or social work roles.

4.1 Similar Posts

It was useful to consider other similar developments in the formulation of this new service. St John's Hospital in Livingston had created a very successful social work post in the eye clinic and ECLO (eye clinic liaison officer) posts have been established by the RNIB in England to provide information, advice and support within eye clinics. Both were contacted and they were very helpful in describing the way in which their service worked and what their experiences had been.

In the early 1990's, Visibility was at the forefront of developing hospital helpdesks across the West of Scotland. The helpdesk programme had been recently evaluated and key findings from this contributed to the shaping of the post.

4.2 Steering Group

Once the proposal was agreed and the funding in place, a short life-working group was formed to consider how the service would function within the outpatients clinic. The group consisted of the Professor of Ophthalmology, Clinical Nurse Manager, Heads of Nursing, Optometry and Orthoptics and the project coordinator from Visibility. The group considered:-

- Location within the department
- Job description
- Day-to-day support
- Data protection and record keeping
- Referral processes

From this larger group, a small steering group was formed, led by Visibility. This continues to provide support and guidance to the project, and meets two to three times a year.

4.3 Early Days

The post was advertised and a very experienced worker with extensive knowledge of social support services for people with a sensory impairment was recruited.

Within a few weeks, a bare room previously used for clinical assessments was transformed into a comfortable, non-medical environment and patients were being referred. From almost day one, several key staff referred patients which proved to be a very powerful message to all staff and within the first four weeks which included the Christmas holidays, over twenty five patients had been seen.

There was some discussion over the name of the service. It had a working title of the “Hospital Information Service” but it was felt this did not adequately describe what the service offers. A new title of “Patient Support Service” was decided upon which reflects the ethos at the heart of the service i.e. a patient led support service which distinguishes it from a more administrative type of information service.

Posters and fliers were produced and distributed around the eye department to inform patients, families and carers and to encourage them to refer themselves. In addition, a letter was sent to each consultant ophthalmologist, and all nursing and reception staff were given information about the service. Because of the geographical spread of patients attending Gartnavel Hospital, contact was made with twelve local authorities to make them aware of the new service.

4.4 Referral Systems

Patients are referred to the service essentially on a drop-in basis. As the service established itself, it became less easy to access, generally because the worker was already with a patient. For some patients a short wait was necessary but that wasn't always possible especially for those who were brought by hospital transport. When this happened, clinic staff recorded patient details so that the worker could make contact by telephone to arrange a suitable time. To facilitate this, a form was devised and distributed widely to clinic staff (appendix 2). On this form, the patients' contact details are logged and details of the eye condition and registration status are recorded so that the worker can contact the patient. This also provides a quick frame of reference for the worker, before seeing / contacting the patient.

4.5 Record Keeping

As evaluation is an integral part of the service, a framework identifying both quantitative and qualitative methods was developed (appendix 3). The framework also informed the recording processes which needed to be put in place.

The first step was to design and pilot a system which allowed a range of indicators to be collected, stored and analysed. For this purpose, a patient enquiry record was developed. On this form, the key points raised by the patient during the discussion and the responses / actions by the patient support worker are recorded. In addition, some relevant personal, social and basic medical information relating to the referral is noted. Over time, the form has been refined and the copy currently being used is appended. (appendix 6).

In terms of data protection, the person's permission is sought and the form is signed showing that they agree to information about them being stored. More from a good practice point of view than anything else, a signature guide was used to help patients sign their name on the consent form. It quickly became clear that this was a revelation for many people. Several said that it was the first time in years that they had felt able to sign their name in a straight line, and almost instantly it gave a boost to their confidence. On the surface, a very small action but with a huge impact, as it seemed to signal to people that there were things which could help. It also seemed to give a message that said the support service understood their needs, and could help.

5. Underpinning principles

Fundamental to the patient support service is that it is patient centred and needs led. Therefore the person, and not the support worker defines the parameters of the discussion. The role of the worker is to listen to the patient's concerns but if asked, can provide information and advice on a wide range of issues. Given that the service is located in the eye department of a hospital, this is a very different approach to the professionally led situation that the patients usually find themselves in.

5.1 Interdependency

Although the aim of the project was to support patients, it is clear there were several other “stakeholders” or “systems” in the process. If the stakeholders did not embrace the project and didn’t change their practice to include patient support, then success would be limited. However, if the introduction of the new service could positively influence the practice of others, then patients would benefit. It was clear that this interdependency would be crucial to the impact of the new service.

This idea of interdependency is centred on a holistic model of practice, which describes working together in a complementary fashion for overall efficiency. In this theory, no one person / action can effect positive change on their own but relies on the interaction of several systems / stakeholders. This is very much the case for the patient support service. Medical, nursing and optometry staff have worked closely with the patient support worker for the benefit of patients. Positive feedback to staff from the patients mean that they continue to refer patients.

The range of methods within the evaluation framework attempts to assess the relationships between the interacting systems of Gartnavel, social services, Visibility, the patients and other support networks.

6. What happens?

The job description (appendix 1) for the post identifies the following range of functions for the post:-

- listening ear for patients, families and carers
- client centred approach to identifying needs
- provide sources of information
- develop good links with social services and voluntary organisations and promote better communication
- secure early follow up in urgent cases

Initially, these functions were seen as a framework for the development of the service. In reality, these five functions now describe the essential elements of the service. Within them, there is a huge diversity in the individual needs and circumstances of

patients using the service. To gain an insight into the day to day functioning of the service two case histories have been included here and a more in depth diary of a typical week is in appendix 4.

6.1 Case Histories

Mrs A

The duty casualty nurse brought Mrs A and her daughter along to the support room. Mrs A was upset, anxious and confused. The possibility of registration had been mentioned at the clinic visit as something that might happen at her next visit in six months time. Mrs A wanted to know what that meant.

I asked her to describe her sight to me and she went on to talk about feeling very stupid about making mistakes as she called it. She was spilling things, not able to pour tea without making a mess, not able to use her cooker very well and having to wait for her daughter to come to “put on the washing machine”. She was having great difficulty telling the time and felt awkward trying to sign her name. She was struggling to read the papers and do the crossword which she used to enjoy. She was also feeling very “down” as she felt she was becoming a burden to her daughter and family. She was frightened to go out alone and she was finding it difficult to recognise people’s faces so was walking passed them in the street.

I explained the registration process and what that meant. I talked in layman’s terms about what ARMD was and gave Mrs A both a leaflet (appropriate print size) and a tape to listen to in her own time. I also provided contact details of the local Macular Disease Society.

I asked Mrs A to sign her name on the consent form with a signature guide. She was thrilled to be able to sign in a straight line and to be told by her daughter that that was the best signature she had seen in a long time. She happily took a guide and I advised that banks have similar type templates for chequebooks. I also demonstrated an easy- to -see watch and she was clearly delighted and smiled, for the first time since entering the room, and said excitedly “*I can see the time, it is three o’clock*”.

The big button phone was also of interest. I advised about BT Age & Disability Services and gave contact details. I demonstrated and gave some basic advice about the use of contrast and good lighting as a way of assisting best use of remaining functional vision. I provided Mrs A with information about big print newspapers and crosswords. Financial benefits were discussed and I advised about contacting the welfare rights officer at Visibility.

We ended on a positive note and they thanked me for my time and for explaining things to them. I gave Mrs A and her daughter a card should they wish to contact me again and they went out of the room looking much happier than when they first came in.

Mr B

On checking the answer phone messages, one was from a young man with diabetic retinopathy who had taken a leaflet home on the previous Friday after being at a clinic appointment. Such was his anxiety, that he had left the message on the Sunday night so I would get it first thing on Monday.

I phoned him immediately and, because of circumstances we arranged that he came in to see me that afternoon. As it happens one of the internal referral forms through my letter-box was from his consultant asking me to contact this patient. His diabetes was causing severe eye problems and he had been advised of blind registration at the clinic on Friday.

He told me that he was having problems at work and had been trying to keep the extent of his loss of vision from managers and colleagues. He felt he just could not cope at work any more and it had got to the stage that he had been sent home. He needed to know what registration meant and what happens now. Nothing I can say can describe the level of despair this young man conveyed. He was feeling totally devastated and was near to tears in my room. His mobility was so bad that he had to hold on to someone for support. All his confidence had gone. With his consent, I cross-referred him immediately, to his local social services department because he needed to be seen urgently.

I have now seen him several times and he talks about feeling much more positive and has acted on much of the advice given to

him. He is now registered as blind, having understood what that meant for him in terms of benefits and services. He is seeing a Department of Employment Advisor via Access to Work and is arranging for a re-training program, via RNIB. He is having mobility training from his local social services department and says feels a bit more in control of his life. He has also made contact with the local diabetic support group.

I last saw him with his mother who also needed to talk about the impact of her son's vision loss for both herself and her husband. She was delighted with her son's progress but needed to talk about how she felt since he had to come back to live with them.

6.2 Response of the Worker

As the cases illustrate, the worker has often very scant information about the patient, if any, so the initial few minutes are critical in the interaction. The worker doesn't really know what emotional state the patient is in and has to react sensitively to the situation. Not every one who contacts the service is in need of emotional support and often the patients are coming with very functional questions. It is also the case that many people start with simple questions about aids and equipment and go on to express much deeper anxieties.

The case histories demonstrate the immediate benefit of the service to the patient. Had the service not been available, Mrs A may have waited six months until the next hospital visit when she was registered. Then, depending on where she lived, another wait of anything between three weeks and six months before her needs were assessed by the local social services visual impairment team and the eventual provision of aids and equipment. This assumes that she agreed to registration, if not, she may never have discovered that aids and equipment were available.

It is likely that Mr B would have been caught in a system that could not respond to his needs for many months whilst he struggled to cope. His loss of confidence, skills and independence would have continued to decline with further implications for his mental health.

There are many other case histories which demonstrate the benefit to the patient of this person centred approach, which can respond to the needs of the individual. Probably the most obvious impact of the post has been that patients who are experiencing great

difficulties and urgently need help are now “fast tracked” into community based help and support.

7. Who uses the service?

A wide range of details are routinely collected on each enquiry. (see appendix 6) This is entered into a database and has been analysed to provide both quantitative and qualitative information about the service. Each contact with the service is coded and described as an enquiry. This allows for the fact that each referral or each patient may be in contact with the service on more than one occasion.

It is also the case that a full data set may not have been collected on each enquiry in these cases the data is coded as unknown. In many cases, it is because the patient did not know the information such as the name of their condition or whether they were registered or not. For some enquiries, especially those dealt with over the telephone it may not be appropriate to ask the age of the person, nor the ethnic group.

7.1 Number of enquiries

The post commenced in December 2002 and by February 2003 about 45 enquiries a month were being made. The project has built on this early success and the number of enquiries averages about 60 per month, though there have been instances of over 100 enquiries being received in one month.

In the first year, there have been 721 enquiries in total to the project. Much of the credit for the success of the projects must go to the clinical staff for their continued support and their understanding of the value of the service to patients. However it is also true to say that they appear to value the service otherwise they would be much more reluctant to refer patients.

Of the 721 enquiries, 611 are first time contacts and nearly 15% are return enquiries.

7.2 Age Group, Gender and Ethnicity

The main client group using the service was female, with just over 60% of the enquiries being from women.

Of the 721 enquiries, there are two main age groups of people using the service; these are the 70-79 and 80-89 years old. If the age-bands are grouped together, then nearly 68% of enquiries are from people over the age of 60.

Worryingly, only 10 patients known to be from an ethnic minority background, have been seen. This is just over 1% of the total number of enquiries. This does not reflect the population profile in Greater Glasgow, especially given there are some eye conditions which have a higher incidence in certain ethnic minority groups. Of the patients from an ethnic background who have been seen, information in an appropriate language has been offered.

“Out of Sight ⁴” is an RNIB report and is a call for action to influence Scottish policy makers of the issues affecting visually impaired people. In the report, it describes the typical person with a visual impairment as:

“Over seventy years old, female, has ARMD, lives alone and is not registered, confused about what registration is and unaware of helpful visual support services.”

As the statistics show, the people using the patient support service are very much in accordance with this profile.

Age Group	Enquiries	Percentage
Unknown	47	6%
Under 19	13	2%
20-29	13	2%
30-39	49	7%
40-49	28	4%
50-59	58	8%
60-69	90	12%
70-79	187	26%
80-89	208	29%
90+	29	4%

7.3 Local Authorities

Nearly half the patients seen by the patient support worker live within the Glasgow City Council area, with another 12% coming from North Lanarkshire and 9% from South Lanarkshire. Significant numbers live in West Dunbartonshire (8%) and East Dunbartonshire (7%).

As Gartnavel is a hospital of regional speciality, patients can come from almost anywhere in Scotland, the longest journey a patient has made is from the remote Island of Gigha, a 250mile return journey by road. It is also worth noting that the patient support worker has seen a number of people from the North of England who choose to attend the retinitis pigmentosa clinic at Gartnavel Hospital.

7.4 Eye Condition

Almost half the patients (48 %) seen have Age Related Macular Degeneration (ARMD). This reflects the national picture of ARMD being the most prevalent eye condition amongst older people.

Retinal problems and in particular Retinitis Pigmentosa was the condition in 14% of enquiries and 8% of enquiries were people with multiple conditions.

Eye Condition	Enquiries	Percentage
ARMD	347	48%
RP	50	7%
Retinal Problems	50	7%
Cataracts	17	3%
Diabetic Retinopathy	39	5%
Uveitis	20	3%
Glaucoma	29	4%
Stroke	8	1%
Macular Problems	6	1%
Neurological	12	2%
Genetic	4	1%
Multiple	57	8%
Trauma	4	1%
Not Known	67	9%

7.5 Registration status

The majority of people (66%) using the service are registered either blind or partially sighted, with 12% being registered on the day that they were referred. Of concern are those patients who are not registered yet struggling with day-to-day life. They are potentially in a more vulnerable position, as they do not have a link through registration with social services. The service is able to provide these patients with information and advice which they would otherwise not get. The service is seeing 1 in 4 patients who are not registered. (26%)

Registration	Enquiries	Percentage
Not Registered	184	26%
Registered Blind	221	31%
Reg Blind today	42	6%
Reg p/s	166	23%
Reg p/s today	44	6%
Not Known	64	8%

7.6 Living Arrangements

If living arrangements arose within the conversation with the patient, the information was recorded and this is the case for 516 of the enquires. Of those, 44% of patients lived alone, and nearly 1 in 3 lived with a partner. Around 4% are sole carers of adults or children whilst having to cope with their own significant sight loss.

Living Arrangements	Enquiries	Percentage
Alone	229	44%
Part of Household	76	15%
Sheltered / Residential	24	5%
Sole Carer of Adult	8	1%
Sole Carer of Children	9	2%
With Carer	1	0.2%
With Partner	169	33%

7.7 Emotional Score

Although a very subjective measure, a score which relates to the emotional intensity of the conversation with the patient was assigned by the patient support worker. On a scale of 1-5, with 5

being very emotional, the picture which emerges, is over 40% of the enquiries have a score of 4 or more. This means that most of the interactions are about dealing with angry, anxious and distressed people and supporting them to articulate their feelings.

Emotional Score	Enquiries	Percentage
0	100	13%
1	184	26%
2	41	6%
3	102	14%
4	95	13%
5	198	28%

8. How the service operates

Within a few weeks, the operational pattern of the service evolved and has stayed fairly constant. Only minor adjustments have been made and very much in partnership with the staff and in response to patients needs.

8.1 Referral to the Service

Essentially there are three main ways of being referred to the project, as a self-referral, by a hospital professional, and by external agency.

Referrer	Enquiries	Percentage
Consultant /medic	329	47%
Nurses	40	6%
Optometry	161	23%
Self	126	18%
Social Services	10	1.4%
Visibility	5	0.7%
Other	28	4%

When referral data is examined, it can be seen that over 50% of referrals have been from medical /nursing staff, with a further 23% from optometrists. However 18% of referrals are patients who refer themselves.

Although very few referrals have come from external agencies, this is an area which could be further developed. Also it is interesting to note that within the referrals/enquiries from medical and nursing professionals, some have come from other medical sources such as stroke liaison, oncology and neurology specialists. This has shown a changing awareness of other medical staff in considering the impact of visual loss on the total well-being of a patient. They have become more aware of the need to seek appropriate support on their behalf instead of treating a given “clinical” condition in isolation. This graphically demonstrates the interdependency spoken of earlier in that the presence of the new service has influenced the thinking and altered the practice of another.

8.2 Telephone Support

In the early days of the service, the telephone call was seen as an opportunity to make an appointment for the patient to attend the service at a more convenient time. It soon became obvious that being able to talk to someone, even on the telephone, was the key to the service. Given that many of the patients are elderly and that a return journey to the hospital was not an easy option, the telephone support service has established itself in its own right as a valuable alternative.

When the data is examined, it shows that more enquiries have been dealt with over the telephone than in a face-to-face situation. BSL interpreting services have been set up for 2 profoundly deaf patients, and support has also been provided to other deaf clients by email and type talk.

Type of Support	Enquiries	Percentage
Face to face	248	35%
Telephone	297	42%
Written	144	20%
Ward	15	2%
Interpreter	2	0.3%

8.3 Referral from the Ward

Contact was made with the wards in the early days of the service and over the first year a total of 15 in-patient cases have been referred. Anecdotal evidence from the patient support worker

suggests that often these cases are more complex and much more emotionally charged. All the ward cases have been people who have suddenly and traumatically lost their sight and what is needed is more of a counselling type of service. There is also the need to confirm that support services are in place on discharge and one of the main tasks has been to alert the local social services visual impairment team.

8.4 BP1 Processing

It had been thought that when the consultant was registering a patient that they would offer the opportunity to talk to the patient support worker. This hasn't happened in any routine way, but about six months into the project, a new system was introduced whereby the worker now gets all of the registration forms (BP1). This is an attempt to deliver a parity of service, and now information is sent to every person who is to be registered within Gartnavel Hospital. The information describes the process of registration, gives details of the local social services visual impairment service and contact details of the patient support service should they wish to make contact. If the worker has already seen the patient, and with their permission, key points from the discussions are forwarded to the relevant social services department. If the person has not been seen by the patient support service, then information is sent out. Although, it has not been logged, it is known that people have contacted the support service through this route, and in some cases have accessed the service on several occasions.

Over the period of June 2003 to December 2003, 144 BP1's have been received and the new procedure of BP1 being processed by the patient support service means that written information has been sent to 20% of total enquiries.

This new process has been greeted very positively from most social services departments, although there was a comment that this had the potential to slow down the system by adding another layer of bureaucracy. This has not happened. It is felt that information on the BP1 form is essentially medical and gives very little insight into the degree of difficulty the person may be experiencing with everyday life. The majority were delighted that they would have additional information on which they could prioritise cases.

9. What people talk about

Conversations with patients are client led, and they are encouraged and supported to discuss how they feel and what they see as their needs. This is central to the ethos of the service. It is not about a standard “package of information” being given but it is about a listening service, and the success of the service thus far, appears to lie with the tailoring of support to the patient’s needs. a needs led service. It also means that the data indicates what the patients have raised at that moment in time. It gives a picture of what they wish to discuss and should not be regarded as a reflecting the totality of their needs. In essence, it may not be the whole picture of any one person but an indication of the most pressing need for them.

From these conversations, key themes have been identified, coded and analysed. Constructing a process which allowed this analysis has taken much refining. In the first few months, a synopsis of the conversation with the patient was recorded in a database. This was very time intensive and as the number going through the service began to escalate, it became too demanding. This data, on the first 350 enquiries, was analysed for recurring themes, prevalent emotions, needs of the patient and actions taken. From this a coding system was designed. The coding sheet is simple and quick to use and much easier for the patient support worker. Brief handwritten notes are also kept by the worker for reference, especially in cases where, with permission, the case is referred onto the relevant social services team.

9.1 Main Categories of Support

There are 27 coding categories (see appendix 6) which can be grouped into three broader areas of support provided. These are emotional support, practical support and written support.

Of the 721 enquiries, nearly 60% of the patients needed emotional support, with over 75% also needing practical support. Another 48% were given written information.

9.2 Emotional Support

When emotional support is further broken down into the coding categories, it can be seen that in almost one third of the interactions, the patient was visibly upset and that less than 20% of patients felt able to cope with their situation at that moment in time.

Emotional State	Enquiries	Percentage
Strong Emotions, Crying, Anger	198	34%
Traumatised	30	5%
Difficulty in coming to terms with sight loss	149	26%
Appears to be coping	113	19%

9.3 Feelings Discussed

Over half of the patients (56%) said that they needed to talk to someone about how they felt, with just under half talking about being scared of going blind or fearful of the future. Loss of skills and independence was a big issue for over a third of people and over a quarter of people (27%) expressed feelings of vulnerability.

Feelings	Enquiries	Percentage
Fearful of future	161	28%
Scared of Going Blind	89	15%
Loss of Skills/independence	224	39%
Isolated	35	6%
Vulnerable/ Insecure	158	27%
Not Being Understood	76	13%
Need to Talk	325	56%

9.4 Registration

Many people wanted to talk about registration and because it was such a prevalent issue, this was coded for and identified separately. Nearly 60 % of people wanted the process explained to them, with only 11% stating that they felt knowledgeable about the process. Those identified as knowledgeable were people who were already registered as partially sighted and were now being re-registered as blind. Given that registration is not relevant for all

enquires, the true figure of those who need an explanation, is probably considerably higher than 60%.

A crucial aspect within this is to explain the term “blind”. Very often the consultant has just told the patient that he is putting their name forward for the blind register, but at the same time tells them that it is unlikely they will go totally blind. People were anxious and confused. The support worker had to spend time discussing “blind” and what residual sight means. Very often people were unsure about useful residual sight and thought that they shouldn’t be able to see at all, causing even more alarm. It is also useful to explain residual sight to families, if present, who often have no idea what the sight loss might be like for their relative or spouse/ partner. This can often help to dismiss the myth that “*they can see what they want*”, a commonly expressed view.

9. 5 Practical and Written Support

In general terms, three quarters of people (76%) needed practical advice and support, and nearly half (48%) were given written advice in appropriate size print or on tape.

There was a range of practical advice given, of which advice on everyday tasks was the most common. This would include talking about kitchen skills, and lighting. One in three people wanted to talk about their eye condition and almost the same number wanted to know about aids and equipment. Over a quarter of people (27%) wanted advice about mobility and travel.

Given that 70% of the total number of enquires were from people aged 60 and over, work related issues were not a big problem. However, if the number of people seeking advice about employment is taken as a percentage of the enquiries under the age of 60, then nearly 40% wanted advice about employment or further education.

Practical Advice	Enquiries	Percentage
Eye Condition Info	193	33%
Advice on everyday Tasks	308	53%
Mobility and Travel Advice	151	27%
Advice about telephones	93	16%
Benefits	56	10%
Housing	42	7%
Aids and Equipment	186	32%
Hobbies and Leisure Advice	76	13%
Clubs and Organisations	64	11%
Employment Advice	43	7%
Talking books, newspapers	68	12%
Further Education	23	4%

9.6 Advice about Social Services

The most frequently discussed issue was that of local support, with 65% of people being given details of how to contact their local social services department. Another 29% were strongly advised to make contact, and in 12% of the enquiries, the needs were so urgent that the patient support worker contacted social services on behalf of the patient and with their permission.

Cross Referral Information	Enquiries	Percentage
Provide SWS details	469	65%
Advise to contact	173	29%
Refer to VI team	68	12%
Refer to generic team	5	1%

10. What people say about the service

Feedback from patients using the service has been collected in two ways. The first is the immediate comments of people within or towards the end of the consultation with the worker; these are recorded on the patient enquiry record. The second method was a telephone interview of a sample of those who had used the service over one month period and then repeated six months later. In addition, return phone calls, letters and cards, comments to the worker have been documented.

10.1 Recorded Comments

In general terms, people have expressed great satisfaction with the service.

“very impressed with whole set up”
“you are doing a grand job”

Almost all of those in touch with the service wanted to express their appreciation.

“thanks for listening to my moans”
“thanks for letting us talk”
“thanks for not making me feel silly”
“thanks for not patronising me”

Clearly what made a difference to people was being able to talk to someone who they felt understood their situation.

“I really appreciate speaking to someone who understands”

Many people valued the time that they were given, and the fact that they were not rushed. Some however did express anger at the way they felt they had been dismissed during a clinic appointment by other staff.

*“it was good to know that someone had the time for me,
which other staff don’t “*
“you make me feel like a person not another number”

A common theme was that they didn’t feel intimidated by the worker and felt it was *“alright to ask daft questions”* but that they didn’t like *“bothering the doctor”*. These questions turned out to be far from silly and often was something thing that made a real impact on their quality of life.

Another consistent theme was in terms of practical advice and factual support. People want information and many were amazed at the range of resources and support that was available to them.

*“at least I know what will happen and that there are things
and people to help me”*
“if she hadn’t told me I would never have known”

“I’ve been coming here for years and no one has ever told me about these things”

Almost every person using the service is given a signature guide and this has proved to be very empowering. It seems to demonstrate to people that there are things which can help and that is important when faced with negative news.

“I’ve just been told I’m going onto the blind register, but I can see the watch you’ve shown me and I can write my name, It’s great....that wee thing to sign your name, is just great”

10.2 Telephone Feedback

Again comments given on the service were very positive and very similar to the recorded comments above. The comments which could be construed as negative comments were, that people didn’t remember talking to anyone or getting any information. Some people found it hard to remember who in particular at the hospital had given them advice. When asked about the new service, they knew they had seen *“a really nice woman”* who had talked to them about things *“she might have been a nurse”*.

For the overwhelming majority of people, the service was seen as being very helpful, and very supportive. They appreciated the fact that they could contact the service again should they need to, as a card with contact details is given to everyone who uses the service.

“when I got home I felt so much better knowing there is somewhere and someone to help”

“just wanted to write to thank you for sending out the information and that thing to sign my name is just great”

Many patients had been attending Gartnavel Hospital over several years, and yet this was the first time they felt they had been given useful information or shown aids and equipment that might be useful.

“she showed me a wee thing that would help me not spill the water from the kettle, and a watch I could see”

Some patients took the time to phone the patient support worker back to say how helpful a particular piece of information had been.

“I phoned the blind golfers and now I’m playing again and it feels great”

“I’ve been to see the Scottish Power IT place and start a course soon and the RNIB people are going to talk to me about job opportunities”

“I’m now going to the theatre again, I didn’t know about the audio description until you told me”

Feedback to the patient support worker has also come from the staff at Gartnavel Hospital who have seen the patients on return visits and have asked for their thanks to be passed on. Again the comments in general relate to how much better they felt being able to talk to someone.

12. Reflections of the Professionals

Whilst it is crucial to have feedback on the service from those using it, it was also important to gather the views of professionals about the new service. This was done in two main ways, a questionnaire (Appendix 5) and interviews.

A questionnaire was distributed to medical, nursing and optometry staff in Gartnavel Hospital and social services staff from two local authorities. The questionnaire was backed up by one to one interviews and a group discussion using the questionnaire as a basis. The feedback was collected over a period of five – nine months. Of the forty questionnaires distributed, twelve were returned but two of those were a collective response from reception staff and optometry staff. Seven, one to one interviews were conducted and two group interviews, one with optometry staff and the other with a social services team.

12.1 Awareness of the Project

All hospital-based staff were aware of the project because of direct contact with the worker, whereas the social services staff had received publicity about the post. Many social work staff knew the worker because of her previous posts within local authorities and valued her skills and experience.

12.2 Benefits of the Project

When asked about the “good” aspects to the project, the dominating themes were in terms of the benefits to the patients and being provided at a time when they most need it. Social services staff felt that the post was an important way of supporting people who are not registered. This was supported by the views expressed when professionals were asked to describe what difference the project has made to patients. It was clear that they felt that it was something very tangible that could be offered to anyone who needed help.

“gives people excellent support, practical and psychological”

“invaluable service where patients can access help”

“provides something positive in an negative situation”

“dispels misconceptions, reassures patients and makes a true difference to quality of life”

“people are very satisfied with the service and feel as if someone cares about them and the difficulties they have with everyday tasks”

When asked about the difference the service has made to staff, the feedback from hospital staff was very much about being able to offer something to patients which they couldn't, either because of time pressures or lack of knowledge

“we appreciate that there is someone able to spend time with patients to supplement our remit”

“a missing part of the team is filled”

“nursing staff felt guilty that they were unable to give patients the time required”

For social services staff, the answers were about being able to identify people who needed support urgently. This is in the context of the fact that the BP1 gives only medical information and social services have no information on the degree of difficulty and the need for social and functional support.

“it is great to have the information with BP1, it helps me prioritise / allocate the case”

“if she sees someone that she really feels needs help we can act and they get seen often as a priority”

It is worth noting that there was no negative feedback. Many of the conversations were around future developments and how the service could be widened.

*“this service is needed in every hospital eye department”
“can I refer patients from Stobhill or the Royal here, they should also be given this support”*

There was a passion about the project and real concerns that the project was only funded for a year. Even in a relatively short period of time staff had come to rely on the service.

“is now an essential part of the service”

Another common theme arising from the evaluation is about the fact that the patient support service can provide a service which hospital staff are unable to give. Several comments were made about the fact that staff didn't know where to get the sort of information that was now being given. There was also the view that staff were learning from the project.

*“patients are given time which is not available to us in a clinic”
“enhances our knowledge of services available”
“now we can offer non optical support by allowing patients access to the network of information local to them which clinicians do not have the knowledge or time to discuss”*

Some staff have written to the patient support worker to express their thanks for a particular case but also comment on the value of the service.

*“It is a service which has been needed for a long time”
“dedicated social support for long term illnesses is vital for the care and comfort of patients”*

Fitting a social model of visual impairment services into a medical model of treatment and care has been one of the most interesting and challenging elements for the service. However the fact that this challenge is recognised and acknowledged by professionals is, in essence, the success of the project. A comment from a senior consultant provides evidence of this.

“the service has produced significant results almost from its first day and the culture change needed to merge medical and social care for a patient has changed remarkably. It is therefore a win win situation for the patient “.

13. Reflections of the Patient Support Worker

From the beginning of the post, the patient support worker was asked to keep a reflective log. The purpose of this was several fold. It provided a picture of the way in which the service evolved, logging key points in the process of establishing a new service. The other purpose was to provide an outlet for the worker to record the experiences. This was important, as the post is line managed offsite from the hospital and the worker does not “fit” within the professions at the hospital and as such has the potential to be quite isolated.

In addition to the reflective log, the patient support worker was interviewed about her perspectives on the project and attributes much of the early success to the groundwork which had been done before the project began. For her, the value of the service is evident.

“the service helps to take away some of the confusion fear and anxiety which surrounds sight loss by offering patients advice where and when it is needed, including social, emotional and functional support. This allows patients to get on as best they can with everyday living”

The main theme that arose was the need to establish professional credibility. The service needed to be shown as a trustworthy and credible source of advice and support for the patients.

For each professional, there was a key case on which hinged the credibility of the service. The patient support worker has made it part of everyday practice to feedback to the staff who referred the patients. Detailed feedback on the specific patient needs, often practical and emotional, and how these were met by the new service has provided tangible illustrations to staff. The patient support worker feels strongly that feedback on cases has demonstrated, to the clinical staff, the value of the post and the way in which it complements their clinical role. It has been important to show that the service fills a gap and that it is neither a

threat nor a criticism of the clinical provision. Also it has allowed for a better understanding of the transition required from the medical world to the social and functional world of someone with a visual impairment. It acknowledges the need for teamwork and the importance of all the roles in terms of caring for the patient. Whilst positive feedback to staff is very valuable, the positive feedback from patients to the worker is very important both in terms of knowing that the service is providing support and in terms of morale of worker.

“it is amazing when they tell you how much you have helped and you see the influence you can have on someone’s sense of well-being”

“they go out smiling and they didn’t come like that, not everyone, of course some are visibly upset but at least they can have a little bit of respite where they can show their emotions”

Of course there are downsides to the post. It can be quite lonely as it is a remote, potentially isolated post, managed and supported by an external agency. However the worker acknowledges the value of immediate line management support from Visibility and the good, formal, professional working relationships forged within the hospital.

The worker was able to identify other sources of stress. They reflect the intensity and the almost relentless nature of the post: -

“one after another, no way to take a step back”

“stress is when the patients just keep coming, a referral through the door while with a patient. You only have a couple of minutes to get your head straight as you can’t delay the patient any longer”

The post has been very fortunate to recruit a skilled and experienced worker who understands the difficulties experienced by visually impaired people but one of the demands of the post is the ability to respond to a wide range of needs.

“you have no idea what a person’s sight problems might be, I often say a core set of things and have to adapt to suit but it is fascinating to find the bit that turns them around - different for each person”

To redress these very real stressful areas, Visibility regularly provides both internal and external supervision/debriefing facilities. This is essential for the professional and emotional well-being and credibility of the patient support worker.

14. Landmarks in the Project

Within the time frame of the project, there have been several “events” which have shaped the evolution of the project. Some of these have already been described such as commitment of key staff to the project. However there have been other landmarks since the project began.

14.1 Open Days and Seminars

Within a few weeks of the project starting an open day was held. This proved to be an ideal opportunity for informal discussions with hospital staff who dropped by to see the displays. For many staff, it was the first time they had met the worker and vice versa. Discussions over aids and equipment triggered an interest and an understanding of what the service might be able to do.

The first opportunity to formally present the work of the project came from a seminar attended with around 40 staff, a mixture of medical, nursing and optometry. The input generated much discussion over the process of registration and the need to support patients at this point in time. The seminar led to much interest from other hospitals, but most notably there was a radical shift in the referral pattern of some consultants. Consultants, who before that date had not referred patients, started to use the service on a regular basis. There appeared to be a clear shift in thinking in terms of the value of emotional support. One particular consultant from another hospital continues to refer, even one year on.

Whilst the statistics presented on that day did increase the credibility of the service, it seems that the case studies made the greatest impact on staff. It allowed them to understand what could and had been done for patients and made them more aware of the social, functional and emotional aspects as a result of an eye condition. There was also direct feedback from consultants to one of whom said:-

“I will be much more liberal when considering registering a patient, now that I understand the benefits”

Perhaps the ultimate accolade and measure of success of the introduction of a social support service within a medical world was an invitation, as the only non-medical speaker of the day, to deliver a presentation at the annual Ophthalmology Symposium of the Royal College of Physicians and Surgeons in Glasgow.

Several other invitations also bear out the acceptance of the project such as induction of medical students into the ophthalmology department.

14.2 Other Contributions

One of the consultants was so impressed by the new service, that an offer was made to buy some equipment for the service from donated funds. The money was used to purchase some pieces of equipment and signature guides. Perhaps the most significant offer was to have blinds installed in the support room to cut out the glare problems experienced by many patients. This seemed to demonstrate a new level of understanding and that the service was an integral part of the care on offer.

Another important link has been BT Age and Disability Services who have provided a demonstration Big Button phone as with NTL's/ Audio phone line and who are very supportive on the service.

15. The Future

It is clear that the service has achieved not only what it set out to do, but much more. The target set for the service in its first year was between 300 – 500 people in its first year, so 721 is an outstanding success.

The second year of this project has essentially been about establishing a quality service and at times, management of over capacity of the service. There is much energy and enthusiasm to further develop the project both at Gartnavel Hospital and on other sites. Within Gartnavel Hospital, there is clear potential to expand the project. However, the service in its current form is at capacity

and consolidation of the existing service requires to be addressed before any new areas of work are developed. For example, ophthalmologists at other hospitals within North Glasgow Trust wish to refer patients to the Gartnavel service. Also there is an increasing number of referrals from other departments so that patients who have sight problems in addition to other major conditions such as strokes, cancer, MS, can benefit from the service. Other areas of development include an increasing awareness of the need for a similar service for children attending Gartnavel and a growing demand from the eye ward. As the enquiry data shows a principle element of the support provided is the demonstration of practical aids and equipment. This is a facility that could be further developed on site.

The introduction of photodynamic therapy (PDT) treatment for age related macular degeneration (ARMD) has brought several new challenges. Before funding was released for PDT, angry patients were being brought along to the service having just been told that although they were suitable for the treatment, but it wasn't currently available at Gartnavel. Whilst this is no longer the case, and the treatment is now available, it is only suitable for one form of the condition and there are many people with ARMD whose condition will not respond to treatment. It is also the case that there are people with ARMD whose condition is too advanced to benefit from treatment. This can be devastating news and the service has provided emotional support to patients finding themselves in this position. The service has also started to support patients who have received the treatment but are left very confused as they have been told that their sight has reached a level which warrants blind registration, yet they are being treated. To the patients, this seems such a contradiction, as the message seems to be they are going blind but they will be treated.

Having set up this service with a strong element of reflective practice and evaluation, there is much that has been learned which could be applied to other similar projects. This report goes some of the way towards sharing this learning but there are many more. A whole range of training events and materials could be developed to support medical, nursing and optometry staff. There is also the opportunity to set up joint training with social services staff. Materials and tapes to provide information to patients would be a very useful step to take.

Developing the project on different sites would require significant funding. But should that be made available, there are a number of options such as mirroring the current provision or introducing a different format such as a peripatetic service. Additionally there is a noticeable gap in a similar specialist service for children.

As a step towards providing a service on different sites, there is a piece of work currently being undertaken to develop a patient information pack. In essence, this is based on the experience of the project and takes the key information and puts it into a pack which can be used in other hospitals. Another idea would be to create an interactive Internet based system, which could be accessed by both professionals and patients where questions and answers could be posted and handled. These ideas all have merit but they are poor substitutes for talking to, and being listened to by, a real person, which cannot happen in an electronic or written format.

This concept of an information pack and training could also be taken forward at a community-based level. Although there has been very limited contact with GP's, there is the potential to share the knowledge and information with primary care based staff. This would allow continued support of the patient within his or her own community and would complement the social services involvement. Many people have asked if the worker could visit them at home, but this is not part of the role. In these cases, the community liaison team from Visibility has been contacted. This is an area of work which could be further developed especially in the light of the new community health partnerships (CHP's) which should be established by 2005. These partnerships being the latest drive to integrate health and social care at a local level.

16. Conclusions

In December 2002, the patient support service at Gartnavel Hospital began. In the 18 months since then, much has been learned and the aim of this report is to share this knowledge and experience.

There were high hopes for this innovative partnership between, Visibility, Gartnavel Hospital and Greater Glasgow NHS Board that a difference could be made to people facing serious sight loss. The project set out to impact on the difficult "patients journey" and fill

some of the gaps in the system. It required the medical world and the social world to meet and work together to provide holistic care. The reality is the project has far exceeded the expectations. Not only has the service become an essential element of the care provision at Gartnavel eye department, addressing the social and functional support needs of a patient facing serious sight problems is now an established and accepted part of the departmental philosophy.

This highly regarded professional service required the integration of a social model of practice into the medical model of practice and for many people to change the way in which they worked to incorporate a new element of service provision. It has come about through the guidance, effort, commitment to good practice and support of Visibility and Greater Glasgow NHS Board. It's success can also be attributed to staff skill, expertise, dedication, and teamwork, and perhaps most of all, because the hospital staff have embraced the service wholeheartedly in their pursuit of the best possible care for their patients. It is this awareness that the service is wider than the patient / worker dynamic that has added to the successful implementation and integration of this project.

The other major strength of the service is that it has at the heart of it, a patient centred approach. Patients are given the opportunity to articulate their needs and concerns and given information and advice accordingly. From this they can make choices and take decisions about issues affecting their quality of life. This is especially powerful because of the timing and location of the service. They have just left a medical consultation where hope of their sight being restored has been diminished or even gone altogether. In the face of this news, referral to the service provides awareness that there are people, organisations and equipment which might help.

The concept of the service arose from visually impaired people describing what would make a difference to them and it is this which has driven the development of the service. Underpinning the development are the following fundamental principles: -

- Immediate practical and emotional support is provided
- Professionally delivered service with high standards of practice

- Holistic service for the visually impaired, their families, carers and related professionals.
- Advice tailored to individual information needs to lessen anxiety and confusion
- Support for patients in regaining and retaining their confidence, skills and independence.

These principles will continue to be the key to the success of the service and any developments arising from it.

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 3. Closing the Gap, Linking health and Social care for visually impaired people. Visual Handicap Group. RNIB 1997
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Appendix 1 - Job description

Job Title: Patient Support Worker

Responsible to: Health Co-ordinator

Line Management Responsibilities: none

Probationary Period: 1 month 3 months

This post is subject to an enhanced disclosure (formerly SCRO checks) under the Police Act 1997 (Part V).

Overview of the Post

The key function of this post is to enable people facing serious sight loss to have early and easy access to information, emotional support, advice and assistance.

The post holder will work directly with eye department patients, irrespective of their registration status and help patients identify their individual needs. From this, people will be referred on to community-based services and the post should be seen as a link between hospital and community based services.

The post holder will be expected to make recommendations that will influence how Visibility support services develop in a manner complementary to existing services.

Confidentiality

In view of the nature of the service and its users the post holder is expected to maintain the highest level of confidentiality in all matters.

Reporting Responsibilities

(1) The post holder will be responsible to the Health Co-ordinator for the successful achievement of the agreed strategic plan, aims and objectives.

(2) The post holder will be line managed and supported by the Health Co-ordinator and Operational Director.

(3) The post holder's performance will be formally appraised on a six monthly basis.

Principal Accountabilities

To work within the policies of Visibility and Gartnavel Hospital

To carry out the necessary organisation, administration and planning as required to the success of the service.

To keep appropriate records of the work undertaken by the service, including monitoring, evaluation and producing reports as required

To make effective use of training opportunities made available through Visibility and other appropriate organisations

Operational Responsibilities

To provide a frontline service offering information and emotional support to those facing serious sight loss.

To develop close working relationships with the hospital staff and other appropriate agencies.

To liaise with all relevant local authority social work departments, be knowledgeable about the services provided in each locality and ensure clear referral pathways are available

To provide information and knowledge about relevant voluntary organisations, self help groups and community based organisations and ensure clear referral pathways are available

To support the implementation of an assessment tool which supports patients to identify their needs.

To work with each patient to provide support based on identified need and where necessary refer, and with consent, refer on to an appropriate agency.

To provide a bridging service between health, community and social services and be the contact person to whom people and their carers can return to for further help.

To develop an administration system for collation and distribution of the BP1 forms to social work departments from Gartnavel hospital.

To establish a resource of appropriate information to support the service

To be able to use computer and internet technology to support the service.

To consult with service users, and staff from relevant agencies regarding the planning, delivery and evaluation of the service.

To maintain Visibility's status as a professional service provider by ensuring that the quality systems are properly adhered to.

To carry out any other duties, as appropriate with grade, that can be reasonably asked to support the development of this service.

Appendix 2 – Internal Referral Form

Referral To Hospital Support Worker Optometry Room 8.

From:-

.....

Date:-.....

<p>Patient Details Sticker: -</p> <p>Patient Telephone No:-</p>
--

Eye Condition

Registration Status

Registered blind today	<input type="checkbox"/>	Previously registered blind	<input type="checkbox"/>
Registered P/S today	<input type="checkbox"/>	Previously registered P/S	<input type="checkbox"/>
Not Registered	<input type="checkbox"/>	Not Known	<input type="checkbox"/>

Any additional information :-

Appendix 3 – Evaluation Framework

1. Introduction

The Gartnavel project is due to commence in November 2002 and evaluation is seen as an integral to the project. It is important that the evaluation framework functions alongside the project and it is defined at the beginning of project.

Many evaluation frameworks exist and common to them all is the concept that evaluation is a continuous process, with several key stages. The first stage is the identification of need which also provides a baseline from which progress can be measured. The process of defining need should be participatory and actively involve all the stakeholders and from this process, aims and objectives can be defined. The aims and objectives can be broken down into measurable elements and defined as inputs, processes, outputs and the long term outcomes.

2. Identification of Need

At a local level, the views of professionals and some services users identified a gap in support especially at the time of diagnosis. From this the work the following objectives for the project were established.

Aim of the project

To establish an accessible information and support service to patients and staff within the ophthalmology clinic at Gartnavel Hospital.

Objectives

To provide emotional support and time to patients attending ophthalmology clinics

To listen to the concerns expressed by patients, families and carers

To supply information to patients families and carers

To work with patients to help them identify their needs

To be a continuing contact for patients

To create a bridge between hospital and community based services

To provide support and information to clinical staff
To establish good working relationships with clinical staff
To identify patients at risk and refer to appropriate agencies

3. Stakeholders

This project is about establishing a new service as part of an existing service and as a bridge to other services. From this it is clear there are many stakeholders who should be included in the evaluation.

They include: -

- Patients / service users
- Families and carers
- Doctors
- Nurses
- Optometrists
- Social workers
- Rehabilitation workers
- GWSSB
- Other voluntary sector orgs e.g. Guide Dogs, Deaf Blind, Sense

4. Quantitative and Qualitative Measures

The key research question in this evaluation is :-

What direct difference does the introduction of this new service make?

The answer to this question can be elicited using both quantitative and qualitative methodologies. If the quantitative parameters are considered, the range of questions which need to be answered include: -

- How many people have used the service
 - How often do they make contact
 - How do they make contact ? e.g in person, on telephone, etc
-

- Who are they e.g. patients, families, staff
- How long is an appointment
- Where do they live
- What age, gender, eye condition
- What type of information are they looking for ?
- What information is given
- How many patients relate to which local authority, BP1 data
- How many urgent referrals and what criteria

5. Qualitative Measures

These more subjective measures can be considered in terms of each of the stakeholders.

- a) Patients
- b) Hospital Staff
- c) Social Work Departments
- d) Voluntary Sector Agencies

6. Methodology and Timescales

It is proposed that several methods are used to collect the quantitative and qualitative feedback on the service.

A patient record sheet will be constructed to provide a synopsis of interaction with each patient but which will also be a mechanism whereby much of the quantitative information is also recorded.

In terms of tracking the qualitative indicators, the following methods will be used :-

- Focus groups
- One to one interviews
- Case Studies
- Anecdotal evidence
- Hospital Worker Reflective Logbook

Focus Groups

It is proposed that at three points over the year, December, April, August, groups of people who have used the hospital liaison service are brought together to discuss their views of the service.

The first meeting will be of people who have recently attended Gartnavel who have not had the benefit of the new service.

Also groups of professionals will also be brought together and provided the same opportunity to share their views.

One to One Interviews

The focus group work will be backed up by one to one interviews with key professionals and randomly selected service users.

Case Studies

It is hoped that a few people are followed up in depth and their stories of their experiences of going through the hospital system and their journey on to social services and the voluntary sector are recorded.

Anecdotal Evidence

Patients and staff will be encouraged to feedback their experiences to the hospital worker and any comments received through this informal method will be recorded.

Hospital Worker Reflective Log

The hospital worker will be encouraged to compile a log of progress which will give insights into the project.

7. Reporting of Progress

At present, a small steering group exists which will have the overview of the project. This group will also receive the regular reports from the hospital worker which will include both quantitative and qualitative information. These reports themselves will inform the final evaluation.

Appendix 4 – Day to day for the Patient Support Worker

Day 1

A busy morning, with 3 referrals from the retinitis pigmentosa clinic who were brought to see me by consultant following their appointment with him. All 3 required advice about work situations and were unaware of Access to Work.

One was being re-registered that morning, from partially sighted to blind and wanted to talk about what that meant and what happens next.

Dealt with some of the referrals from the day before. Phoning back to people with supportive advice ranging from where to find a local blind club, where to get a talking clock, how to order a big print newspaper, and where to get advice about screen enlargement software for computers. Sent out relevant pieces of information whilst processing registration documents to their appropriate local authorities.

In the afternoon, attended a steering group meeting with Eye Consultant, Nurse Manager, Head Optometrist and my own line manager. Regular meetings are essential to good working relationships and maintaining good practice standards.

Dealt with several other referrals restocked the information stands in the public reception areas and caught up with paperwork. Started to prepare at presentation for Royal College of Physicians and Surgeons in Glasgow Annual Ophthalmology symposium. I would be the only non-medical input to the day.

Day 2

First patient brought along was a profoundly deaf young woman, a widow with 2 young children was relying on her aunt for interpretation. This was not satisfactory, from anyone's point of view, so I re-arranged for her to come back to see me and I arranged an independent BSL interpreter to be there. It was important that she could talk with me in privacy, herself, as she had some very personal issues she wanted to talk over. She was unaware of benefits to which she certainly had entitlement

because of her circumstances and I gave her advice about how to access these. I advised her to re-contact her local visual impairment support services, as it had been a number of years since she had any contact and she was in need of an updated re-assessment as her sight had deteriorated.

The afternoon saw several referrals via the Low Vision Aid clinic. Most were “typical” people with ARMD, that is not registered and on their confusing journey through living with sight loss. They were unaware of any helpful services or where to access them. One woman was in tears as she looked at my demonstration big-button phone and easy –to-see watch, both of which she could read. Her daughter was so pleased for her mother and wanted to know where she could purchase these items since they would be of immediate benefit. I got a thank you phone call a couple of weeks later to say they had now received the exchange of phone via BT and they had purchased several other useful items from the contact advice I had given them.

Day 3

Several support /advice phone calls to attend to and then to help support the blind registration of someone who had experienced a traumatic sight loss within days. Saw this man just after the consultant had said he would be registering as blind and as I witnessed the form being signed, I tried as best I could under the circumstances to explain, “what happens next”.

Sometimes you just need to sit and listen, and that is what my job was after the consultant had gone. Both this man and his wife were traumatized by what had happened so suddenly and permanently and in this case they needed to talk about their anxieties. I later cross referred this man to the appropriate local visual impairment social services team having consulted on this occasion with the hospital social worker as there were generic care issues as well as specialist visual impairment issues to address. I must be aware of what I can and cannot do and when I need to refer on to other appropriate support services.

Saw an elderly man with ARMD just after he was registered blind. He was with his wife. He had not received well the news of “nothing else can be done “and asked the usual question, “what

happens next?" I encouraged him to tell me in his own words what he felt about his sight loss and his diminished quality of life.

We went on to discuss some positives in terms of what he was able to do. In the course of discussion it emerged that he had played professional football for one of Glasgow's top football teams in the 1940's. I was able to arrange a monthly news tape of his particular team, which he had not known about. He has since phoned back to say how much he enjoys the tape and has in fact, joined a blind party who attend football matches with sighted guides.

He feels his quality of life has improved and was able to articulate that he had got this kind of support at a crucial time when he felt that nothing else could be done. He is still on a 5 month waiting list to be visited by his local Social Services Visual Impairment Team following his blind registration.

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Appendix 5 - Questionnaire

Gartnavel Eye Dept Patient Support Service

Evaluation is an integral component of this project. To help us assess the impact of the service, we would be grateful if you could complete the following short anonymous questionnaire. Please send completed questionnaires to Shelagh Palmer, Visibility, 2 Queen's Crescent, Glasgow G4 9BW. Thanks for your help.

1. What do you think is good about the project?
2. What do you think could be improved?
3. Have any of your clients used the patient support service?
Please circle.
Yes / No

What impact, do you think the patient support service has had on these clients?

4. What difference do you think the introduction of this service has made to visually impaired people?
 5. What difference has the service made to you / your service?
 6. Any other views or comments?
-

Appendix 6 – Patient Enquiry Record

Enquiry Record	Patient Support Service	Eye Department, Gartnaval Hospital
Patient ID:		
Name		
Address		
Post code	Telephone No.	
Age:	Gender	Ethnicity
Eye Condition		
Additional Disability/Conditions		
Registration Status		Living Arrangements
Type of Support	1:1 Telephone Written	Local Authority
Time Taken	<input type="checkbox"/> 0-9 <input type="checkbox"/> 10-19 <input type="checkbox"/> 20-29 <input type="checkbox"/> 30-39 <input type="checkbox"/> 40-59 <input type="checkbox"/> 60-89 <input type="checkbox"/> 90+	Emotional Score Low: 1 2 3 4 5 :High
Referral Method	<input type="checkbox"/> BP1 <input type="checkbox"/> Other	Referrer

I consent to the details of this form being stored for one year and being used for the provision of further services.

Patient Signature.....

Date.....

Guide used

Patient Support Worker Signature.....

Provided

Enquiry Record
Notes

Patient Support Service

Eye Department, Garthnaval Hospital

SUPPORT GIVEN		PRACTICAL ADVICE	
Emotional		1. Registration	
Practical		2. Services Available	
Written		3. Eye Conditions	
Process BP1		4. Everyday Tasks	
Cross Refer		5. Mobility and Travel	
		6. Aids and Equipment	
EMOTIONAL STATE		7 Telephone Use	
1.Strong Emotions, crying, anger		8. Benefits	
2.Traumatised		9. Housing	
3.Difficulty in coming to terms with sight loss		10. Employment advice	
4.Appears to be coping		11. Further education	
		12. Hobbies/ Leisure Advice	
FEELINGS		13. Clubs and organisations	
1.Fearful of future			
2.Scared of going blind			
3..Loss of skills/independence		PRACTICAL ACTION	
4. Isolated		1. Set Up talking tapes	
5. Vulnerable / insecure		2. Provide signature guide	
6. Not being understood		3. Provide SWS Details	
7. Not being Listened to			
CROSS REFERAL INFORMATION		Notes	
Advise to Contact SWS			
Refer to Generic Team			
Refer to VI Team			
Date			
Signature			

Appendix 7 - The Patients Journey

