

THE IAIN RENNIE HOSPICE AT HOME

SURVEY OF FAMILIES OF PATIENTS

Purpose

To find out how much families of patients knew about the non-nursing aspects of the IRHH service whilst receiving care.

Reason for Survey

There is anecdotal evidence which suggests that patients and families are not aware that the IRHH is a charity which relies heavily on fundraising and donations. This may affect their attitude to the charity following bereavement and may inhibit their future support through donations, fundraising, legacies and volunteering.

Visitors to traditional Hospice In-Patient Units and Day Care facilities learn much more about the Hospice, its costs and facilities and have the opportunity to pick up information and ask questions. The IRHH does not have this benefit, and the relationship between our nurses and patients and families are critically important in laying foundations for an ongoing relationship with the IRHH following bereavement.

The financial situation at IRHH means that we can not afford to ignore this potential source of support. Firm evidence about awareness which would result from a properly conducted survey would enable the IRHH to produce a strategy to deal with any problem identified and maximise this potential.

Sample Group

In April 2001, 116 next of kin of patients who had died between 2nd September 2000 and 8th January 2001 were sent a questionnaire. A minimum of 3 months and a maximum of 6 months had elapsed since their bereavement. A covering letter explained the purpose of the survey and a Freepost envelope was provided for their reply. The sample group represented all of the patients cared for within the chosen time period.

Questionnaire

The questionnaire was presented in an attractive, easy to read A5 leaflet format. 10 questions were asked with multiple choice response tick boxes. Some questions invited a written response or comment and these have been included in the results. There was also a concluding section with an opportunity to give general comment. These have also been given in full.

Response

69 questionnaires were returned representing a 59% response.

Issued	Nursing Team	No. Returned	%
33	Dacorum	19	57.58
5	Paediatric	3	60.00
22	Ridgeway	17	77.27
31	South Bucks	16	51.61
25	Wycombe	14	56.00
116	Totals	69	59.48

A closing date of 31st May was set, but questionnaires returned after this date have been included.

The data has been processed and the results are given below. Where more than one answer to a question was possible, the percentages have been calculated on the total number of answers.

SURVEY OF FAMILIES OF IAIN RENNIE PATIENTS – RESULTS

Please tick the box that best describes your understanding of each statement or answers the question.

1 The Iain Rennie Nurses are part of	
A local Charity	76%
A national Charity	19%
The National Health Service	2%
Don't know	3%
Other (please specify)	0%

2 The Iain Rennie Nurses are	
Paid	71%
Volunteers	19%
Don't know	10%
Other (please specify)	0%

3 Is the Iain Rennie Hospice At Home's financial position	
Strong	3%
Weak	41%
Satisfactory	23%
Don't Know	33%

4 How many patients are cared for each year by the Iain Hospice At Home?	
0-250	6%
251-500	18%
501-750	12%
751 plus	6%
Don't know	58%

5 The Iain Rennie Hospice At Home gets its income mainly from	
The National Health Service	1%
Fundraising and Donations	76%
Legacies	18%
Don't know	5%

6 Did the nurses give you all the information you would have liked about the non-nursing side of the organisation?	
Yes	77%
No (if no, please give details of what was lacking) Comments: <ul style="list-style-type: none"> ◆ I didn't ask. I was too involved in their help ◆ No information given ◆ We got to know very little. ◆ I would have liked to have had more info about ways to give/raise money for charity. ◆ The nurses were excellent but my interest was for my wife at the time, as was the nurses 	17%

<ul style="list-style-type: none"> ◆ I am beginning to know now but did not at the time. We were all focused on the care of my mother. ◆ Nothing was lacking. ◆ Information given but I did not read it. 	
Don't know	6%

7 If you have private medical insurance, did the nurses inform you that the cost of the Iain Rennie service could be claimed?	
Yes	6%
No	28%
Don't Know	6%
I don't have private medical insurance	61%
Comments: <ul style="list-style-type: none"> ◆ I am not sure if my private health insurance would have covered the costs but I was not informed that it possibly could be. ◆ Was not asked about medical insurance nor informed about disability allowance ◆ I was going through a terrible time and the nurses were sensitive to my feelings. See also letter re IRHH to claim from PPP. 	

8 How much do you think it costs to run the Iain Rennie Hospice At Home service each year?	
Less than £100,000	2%
£100,001 - £250,000	13%
£250,001 - £500,000	28%
£500,001 - £1,000,000	19%
£1,000,000 - £1,500,000	21%
£1,500,001 plus	17%

9 When would it have been acceptable for us to approach you about supporting the Hospice At Home in some way? (eg. through donations, volunteering etc.)	
During the lifetime of the patient	23%
Within one month of their death	14%
2 - 3 months after their death	19%
4 - 6 months after their death	34%
Never	11%
Comments: <ul style="list-style-type: none"> ◆ Leave the decision to the family. Different people react differently as time passes when coping with cancer. 	

10 Have you helped, or did you consider helping, the Iain Rennie Hospice At Home in any of the following ways?	
Donations in lieu of funeral flowers	44%
A legacy	0%
A one off donation	18%
Regular donations	11%
Helping as a volunteer	4%
Other (please specify)	18%

<ul style="list-style-type: none"> ◆ Organising fund raising ◆ Giving books and tapes to the local IRHH shop ◆ I would like to find a way to support IRHH through my business ((Company) in Hazlemere) ◆ Under consideration ◆ Light a candle. ◆ 3 Hospice lottery ◆ Christmas Lights. In future I hope to generate income with sporting events and marathon running ◆ items given to IRHH shop ◆ I always visit the Tring Shop and usually buy something. It must help in a small way. ◆ Have been Patrons for several years. ◆ I belong to (a) WI who have nominated IRHH as our charity of the year. ◆ Have taken note of whereabouts of Book Shop and general shop and am supporting. Had intended to attend charity concert but date inconvenient. ◆ Clothing donations for your shop ◆ Clothes given to Tring shop ◆ Fund raising events supported ◆ I now have limited money but I will help with donations when possible. ◆ About £2000 was given ◆ Too soon 	
I did not feel able to help	5%

<p>If you have any comments on any aspect of our service or about this questionnaire, please give details here or write to us in confidence at the address on the front page.</p>	
<ul style="list-style-type: none"> ◆ I thought the service and care provided for my mother was wonderful. ◆ Your service I received with help for my husband was excellent. Thank you. ◆ Your nurses are brilliant ◆ I am sorry but he died before he could benefit from your services but the help I have received is very, very good. ◆ I would consider helping as a volunteer and would like to make a one off donation. Your staff were wonderful to both my wife and myself. ◆ For the carer, you are a lifeline. Good luck for the future. ◆ Service wonderful, thank you. ◆ The service given to my wife and me over the period of 18 months was excellent plus the knowledge that there was always someone to refer to when a crisis arose - whatever time of day and help would be there. ◆ Helping as a volunteer, what kind of help is needed? ◆ I would have liked to have known more about the team before we needed them. 	

- ◆ The IR nurses gave very valuable care, help and assistance during the latter part of my wife's life at the time when most needed. I am very grateful. Thank you.
- ◆ If you can advise me on how we might be able to support your fundraising events through our shop, please call me on (telephone numbers). Thanks.
- ◆ A vital service and much appreciated.
- ◆ Our involvement was less than 1 month. We only saw someone 3 times. Things may have been different had it been longer.
- ◆ I was extremely grateful for the help and support given to me during my husband's illness. Until that time I was unaware of IRHH's existence and heard of you via my GP.
- ◆ I was very pleased with the care given and appreciate all the support my family received.
- ◆ Returned but not filled in!
- ◆ Letter enclosed ...Outstanding service. Want newsletter and Home Box
- ◆ Bereaved wife was disappointed as no contact was made from IRHH staff after husband's death despite donations. A physical welfare call was missing.
- ◆ At the very difficult period of (patient's) illness (not cancer), more support would have been acceptable. The helpline was our life-line and the nurse responded so well
- ◆ I think the service is excellent.
- ◆ I would be interested to receive more information about the Iain Rennie Hospice At Home.
- ◆ Returned but not filled in!
- ◆ I think your nurses did a wonderful job at a difficult time
- ◆ You know how much your help meant to (name) and me.
- ◆ We didn't get to know the nurses very well, but for the last few weeks of my husband's life they were wonderful and very caring
- ◆ I put your name forward to the May Day Committee at Kingston Blount but unfortunately this was cancelled due to foot & mouth. Sydenham Fayre will be donating a quarter of their proceeds
- ◆ My husband only lived long enough to have the pleasure of three visits from your nurses and thought they were a great help to him. For this I thank you.
- ◆ I have only praise and immense gratitude for the service Iain Rennie gave us. I don't know much about the organisation per se because (IR Nurse) who cared for our daughter (name) has been a friend of mine for 30 years, so no prior discussion was necessary. I will be of any help I can.
- ◆ A very professional service - invaluable at the time of death & immediately after. We are heavily involved in fundraising for childhood cancer so would consider helping IRHH in future.
- ◆ I cannot speak highly enough of the loving care and help given to me during my husband's illness and subsequent death. I also much appreciate their follow up after his death to know how I am coping.
- ◆ I feel I know very little about you but I am eternally grateful for your loving care of my husband in his last months and your care and concern for me after his death. Thank you all.

CONCLUSIONS & RECOMMENDATIONS

Questions 1 to 5 and 8 dealt with the respondent's general knowledge about the Iain Rennie Hospice At Home.

- ◆ Although 76% knew that the IRHH is a local charity, 24% thought that we were either a national charity, part of the National Health Service or did not know.
- ◆ 71% of respondents knew that IRHH nurses are paid, but an amazing 19% thought that they were volunteers.
- ◆ Knowledge of IRHH's financial position was mixed, but 33% did not know enough to give an answer and gave a "don't know" reply.
- ◆ The approximate number of patients cared for by the IRHH operation was not known by 58% of respondents.
- ◆ Most people knew that the IRHH relies on voluntary income. 76% thought correctly that fundraising and donations was our main source of income. Surprisingly, 18% thought (incorrectly!) that legacies were our main source of income but no respondent indicated that were considering making a bequest in their will.
- ◆ The scale of the IRHH operation in terms of annual expenditure was understood by just 21% of respondents. However, the largest group of respondents thought that the IRHH spent between £250,000 and £500,000 per annum although 57% overall had a reasonably good impression of the size of our organisation.

Question 6 asked specifically about the non-nursing side of the IRHH.

- ◆ 77% of respondents felt that they had enough information.
- ◆ However 17% felt that the information provided was inadequate and this is supported by the comments.

Recommendations:

1. General information about the IRHH should be enclosed as part of a Referral Pack with easily absorbed facts or questions with answers explaining key facts.
2. Nurses should be kept up to date with basic information about our general and financial circumstances and funding needs.
3. Nurses should be well informed and encouraged to give information and be proactive with patients and families about non-nursing issues.
4. Nursing teams should have appropriate involvement with fundraising groups and other supporters to build a greater understanding of each others' roles.
5. General publicity about the IRHH should communicate more information about our situation.

Question 7 asked about Private Medical Insurance (PMI).

- ◆ 61% of respondents told us that they did not have PMI. This implies that up to 39% do.
- ◆ 28% of respondents were unaware of the possibility of making a PMI claim despite the fact that this is a specific question on the IRHH Patient Form. (Sample Form appended).

Recommendation:

6. As this is a major potential source of income, urgent steps need to be taken to ensure that the existence of PMI is established either by the key nurse on referral or by writing to families to inform them about it.

Question 9 attempted to establish when it is appropriate for patients and families to be approached about donating, fundraising and volunteering.

- ◆ The largest group of respondents, 34%, felt that 4 to 6 months would be appropriate, closely followed by 19% saying that 2 – 3 months was appropriate. (Our current newsletter approach is sent between 6 and 10 months).

- ◆ Interestingly, the next largest group (23%) felt comfortable with an approach during the lifetime of the patient.
- ◆ 11% said that such an approach should never be made.

Recommendations:

7. Newsletter approach (with "opt out" option) to be sent out 3 – 7 months after bereavement instead of 6 – 10 months. Approach to have a sensitive but stronger "appeal" message giving clear and concise information about the many different ways of supporting the IRHH.
8. Information about fundraising and a newsletter to be included in Referral Pack.

Question 10 provided a range of useful responses relating to ways of supporting the IRHH.

- ◆ The responses show a great general willingness to support in some way with only legacies receiving a 0% response.
- ◆ Just 5% of respondents felt unable to help in some way.
- ◆ In memoriam donations (44%) were the most popular way of supporting.
- ◆ The comments reveal great interest in the shops and this underpins the vital importance of ensuring that shop staff and volunteers are helpful and sympathetic to people bringing in goods to sell who are often bereaved.

Recommendations:

9. We can feel confident about being proactive in asking families to support us and providing them with information about the different ways of doing this. This applies to both fundraising and volunteering initiatives.
10. Improve communication with in memoriam donors.
11. Urgent training of shop Managers and volunteers is needed to ensure that bereaved families' needs are understood and that they receive a warm, friendly response on all occasions.

The comments section produced a predictably warm response to the care provided by the IRHH.

- ◆ However, it did reveal that a number of people who were keen to help did not have adequate information about the ways they could do so.

Recommendations :

12. Ensure that adequate information about the different ways to support the IRHH are included in the Referral Pack and in mailings to families after bereavement.

CONCLUSION

The survey endorses many of our feelings about the relationship between nurses and patients and families. It also shows clearly that improved communication is needed and, if achieved, would bring substantial benefits to the IRHH and families of patients.

Robert Breakwell

Appeals Director

16th July 2001