



Rubislaw Park End of Life Care Beds Test of Change Evaluation.

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Key Points

- As part of Aberdeen City Health and Social Care Partnership's (ACHSCP) winter planning and a whole system pathway of care, five interim beds within Rubislaw Park Nursing Home were approved for use in December 2021 for End-of-Life Care.
- An evaluation was conducted of the service taking into account the views from patients' next of kin, the team at Rubislaw Park and the Hospital at Home (H@H) team alongside other services who came into contact with the patient and service.
- Thirty patients were admitted to Rubislaw Park between January-June 2022. This gave a bed occupancy level of 43.3%.
- Patients were referred from 16 different GP Practices across Aberdeen City and patients who were referred came from an equal spread of Scottish Index of Multiple Deprivation (SIMD) areas.
- 88% of the next of kin surveyed felt that the patient's needs were fully met during their stay
- 88% of next of kin surveyed would recommend the service to others who may find themselves in a similar position.
- When asked to rate the experience of working with the team at Rubislaw Park, the H@H team rated them 9 out of 10.
- The evaluation recommends for the service to continue with the following points considered:
 - o Review the environment surrounding the End-of-Life beds
 - The referral pathway should be scaled up to allow patients to be referred from all acute services
 - o The communications plan requires to be reviewed and enhanced
 - Further evaluation to be conducted 18months after the pathway has been scaled up.

Executive Summary

Background

As part of Aberdeen City Health and Social Care Partnership's (ACHSCP) winter planning and a whole system pathway of care, five interim beds within Rubislaw Park Nursing Home were approved for use in December 2021 for End-of-Life Care. Originally approved for a 6-month test of change by the Integration Joint Board (IJB), this contract was extended to November 2022 to allow for an evaluation to take place outlining a recommendation and for further service negotiations to take place to ensure service continuity dependent upon the outcome of the recommendations.

Methodology

In order for a robust evaluation to take place, the Steering Group and Evaluation Team cocreated an approach to ensure that feedback could be taken into account from all users of the service. This centred engaging with the following key stakeholders:

- Next of kin/carers
- The Rubislaw Park team
- Hospital at Home (H@H) team
- Other staff groups who referred into the service or continued to be involved with the care of the patient.

Results

Between January and June 2022, 30 patients were admitted to Rubislaw Park for End-of-Life Care beds as funded for by ACHSCP. The bed occupancy levels during the period of the evaluation were 43.3%. The patients were referred from a variety of GP Practices across Aberdeen City.

Feedback from the patient's next of kin regarding the service received from Rubislaw Park has been positive and there was confidence in the service, patients reported to feel safe and secure knowing that there was someone there 24 hours a day and importantly, it allowed family and friends to leave their caring role and resume their role as family or friend.

The services who worked alongside the Rubislaw Park team, including H@H, Macmillan Nursing, General Practitioners (GP's) and Secondary Care referrers also reporting positively, with one respondent from the H@H survey reporting that "The team at Rubislaw are excellent, motivated, caring and professional at all times".

Conclusions and Recommendations

This report concludes that the service provided from the team at Rubislaw Park was well received by patients, family and carers, and staff. The need for this service is only likely to

increase with current population projections. It recommends that the service is continued with some attention paid to the following areas:

- 1. The environment surrounding the End-of-Life beds should be assessed
- 2. The Referral Pathway should be scaled up to allow referrals from all acute services to ensure that the bed base occupancy is fully utilised while ensuring that continuity of care from the Rubislaw Park and H@H team can continue.
- 3. Communications Plan requires to be reviewed.
- 4. A further evaluation to be conducted 18 months after the referral pathway has been scaled up and implemented.

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1. Introduction

The population of Aberdeen City is changing, and projections show that the number of people living in Aberdeen City aged 75 and over will increase by 28.2% by 2033 (National Records Scotland, 2018). In addition, there has been a 25% increase in people living with long term conditions, and by 2035, it is estimated that 66% of adults over 65 will be living with multi morbidities (NIHR, 2018). It is expected that the number of people dying each year will increase by 16% between 2016 and 2040 (Scottish Partnership for Palliative Care, 2021). Therefore, how health and care services are planned and delivered need to be adapted accordingly.

Taking into account the population projections of Aberdeen City, it can surmised that there will be an increase in Palliative and End of Life (EOL) care needs. End of Life care can be defined as care that "addresses the medical, social, emotional, spiritual and accommodation needs of people thought to have less than one year to live. It includes a range of health and social services and disease specific interventions as well as palliative and hospice care for those with advanced conditions who are nearing the end of life." (WHO, 2015). Up to 50% of health and social care delivery takes place in the last year of life, with spending typically increasing in the last days of life, when care at home or in-patient bed usage is at its greatest. (Lyons, P. and Verne, J., 2011.). On average, someone in the last year of life will spend one month in secondary care, spread out over several admissions. The total cost for this is around £10,000, with inpatient admissions accounting for over 80% of this (Diernberger, K. et al, 2021). Demand across Scotland within Acute hospital settings is increasing, and this cohort of patients in particular require access to appropriate nursing care in the most appropriate location for their needs.

General trends in Scotland show that the number of deaths which occur in acute hospitals has fallen from 58% in 2004 to 50.1% in 2016 (Diernberger, K. et al, 2021). The Grampian Wide Strategy Framework for Palliative and End of Life Care (Draft) (2022) shows that in 2019, 910 deaths occurred at Acute Hospitals, which accounted for 42% of all deaths in Aberdeen City. A further 26% occurred in domiciliary locations (likely at home) and 24% happened in care/nursing homes. In addition, 164 deaths (7%) occurred at Roxburghe House. Similar figures can be found in 2020 and 2021 where 44% and 46% of patients died in acute settings. With the number of people dying in acute care reducing and the population increasing, the Rubislaw Park End of Life care beds service looks to ensure that for those people who need increased levels of nursing care on an around the clock basis which the family cannot provide, but that does not warrant acute care intervention, that there is an appropriate option within the community that supports the patient and their family.

2. Methodology

2.1 Service Model

The Palliative and End of Life Care needs of patients in Grampian can often be effectively managed by primary and secondary care resources. For those patients who remain in the community a collaborative approach across health and social care teams helps to support and meet their needs. General Practitioners (GP's), Community Nursing, Macmillan Nursing, Hospital at Home (H@H) and Care Management alongside informal carers may be involved in the provision of individualised care with input from other teams as and when needed.

A perceived a gap exists where the patient (and their support structure) requires a level of nursing care that cannot be provided at home but does not necessarily warrant admission to an acute or specialist setting. A solution was investigated which would look to alleviate the situation for carers, allowing them to resume a supportive role while providing an elevated level of nursing care for the patient. As part of the whole system pathway review, and winter surge planning, five interim beds within Rubislaw Park Nursing Home were approved for use in December 2021 for End-of-Life Care. The Nursing team at Rubislaw Park were already skilled in delivering palliative care and a small number of the Care Home nursing team had received specialised palliative care training in order to be able to set up and administer medication through syringe drivers which normally would require input from the District Nursing team. Nursing care and management resides with the nursing team within the home, and support is provided where appropriate by the Community and Out of Hours nursing team and Hospital @ Home. The beds were financed for use by ACHSCP.

The first phase of the project focused on establishing the pathway for community referrals through district nursing and general practice via H@H. In May 2022, the End-of-Life Care pathway was expanded to receiving referrals from the Acute Medical Initial Assessment and the Emergency Department (AMIA/ED) within Aberdeen Royal Infirmary (ARI), Rosewell House, MacMillan Nursing and Ward 102 - Frailty Unit, Aberdeen Royal Infirmary (ARI).

The overall ambition for the Service was to provide increased End of Life Nursing Support on a 24/7 basis for patients and their next of kin who are unable to continue living and being supported at home. This was to allow for the most appropriate care to be provided at the right time for the patient whilst also providing support to their family.

2.2 Evaluation Approach

Much of the literature around End-of-Life care focuses on the 'preferred place of death' as a measurement. This is a subjective measure, and it may change considerably over the course of the patient's pathway. It also gives no real indication of the quality of care received by the patient or the experience of the next of kin/carer (Hoare, 2022). This evaluation wanted to attempt a more holistic review of the experience of the staff, patients and next of kin/carers. In order to do this, the evaluation explored three different areas:

- 1. Understand the realised benefits for patients, next of kin/carers and staff
- 2. Understand whether the service is managed in an effective manner, regarding the business processes, communication etc.
- 3. Based upon the findings from Point 1 and 2 above, make an assessment and recommendation regarding the future provision of the service.

To answer this, an evaluation framework was co-created with the Steering Group to meet these needs. The following gives an overview of the main methods used to gather feedback and assess success.

2.2.1 Patient Data.

Throughout the test of change at Rubislaw Park, demographic data was collected regarding the patient's stay. The data collected was largely quantitative in nature and allowed the evaluation team to review the patient's referral criteria, geographic spread and age demographic. Due to the nature of the patient's condition at the point of entry into the service, it was deemed inappropriate to ask patients to directly take part in the evaluation process. Consent was received from the next of kin to take part in the Service Evaluation.

The following list gives an overview of the patient data captured:

- Name
- Date of Birth
- Postcode
- Scottish Index of Multiple Deprivation (SIMD*) Score
- GP Practice
- Palliative Performance Score (PPS**) upon Referral
- Referral Source
- Referral Date
- Discharge Date
- Length of Stay
- Reason for Discharge
- Next of Kin Name and Phone Number

*SIMD is the is the Scottish Government's standard approach to identifying areas of multiple deprivation in Scotland.

2.2.3 Carer/ Next of Kin Survey

As part of the data shared with the Evaluation Team, the next of kin details were used as a means to conduct a survey to understand their experience of the service and what they perceived the patient's view of the service to be. The Rubislaw Park team informed the next of kin that a service evaluation was due to take place and asked for their consent to share these details. This meant that the data collected within was categorised as a service evaluation, meaning no ethical approval was required.

The survey was created using Microsoft Forms and the next of kin was contacted following the patients discharge and they were given the option to complete it using an online link or over the telephone during a conversation with the evaluation team. Ten questions were then asked to the next of kin relating to the service received at Rubislaw Park, whether they felt any improvements could be made and whether they would recommend the service to others. Results from the survey were gathered anonymously.

Due to the nature of the service and the individuals who were taking part in the questionnaire, input was sought from specialists in palliative care on how the questions were formulated and where appropriate, signposting was given to be reavement support resources in case the discussion evoked a strong emotional response from those involved.

Results received were a combination of qualitative and quantitative data. These were analysed using thematic analysis in order to capture key themes that were identified from feedback, and key quotes were lifted from the data where appropriate.

2.2.4 Feedback from Rubislaw Park Palliative Care Team

A Focus Group was held with three of the Nursing Team from Rubislaw Park in order to discuss whether they felt the test of change had been successful. The discussion focused on the benefits, challenges and any comments regarding the pathway and business processes surrounding it and whether they could suggest any changes to the service if it was to remain in place in the future. The information gathered was qualitative and was used to gain their perspective of the service. It was later analysed by the evaluation team using a mind map to pick out themes.

2.2.5 Feedback from the Hospital at Home (H@H) team

A questionnaire was sent to six key members of the Hospital service who work with the team at Rubislaw Park on a regular basis. They were questioned on a number of criteria including day to day communication and management, the referral process and the overall care of patients.

^{**}PPS is a tool used for assessing a patient's functional status

2.2.6 Feedback from Referrers/other Staff Groups

Feedback was sought from services who had referred patients to the service. Other services who worked closely with the patient were also contacted and asked whether they would like to take part in the evaluation. A Microsoft Form was created and tailored to each service. Responses were largely qualitative in nature and were analysed as part of the evaluation process.

3. Results

3.1 Patient Profile

Between 5th January and 30th June 2022, 30 patients were accepted into the End-of-Life Care Service at Rubislaw Park. In the majority of cases (28), clinical responsibility remained with the GP, while in 2 cases clinical responsibility was passed to H@H.

Table 1 displays the general patient characteristics.

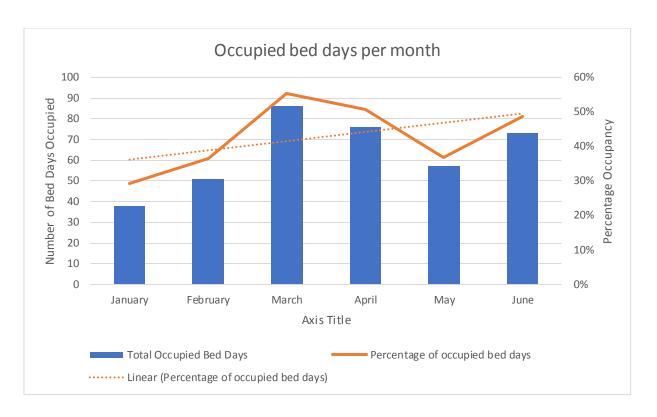
Patient Characteristics	Total
Caseload, N	30
Gender, Male	53.3%
Age, mean [Range]	80.9 [67-97]
SIMD Scores	
1	9.7%
2	29%
3	9.7%
4	9.7%
5	29%
Not reported	13%
Palliative Performance Score (PPS), mean	31%
Days on caseload, mean [range]	12.7 [2-70]

Table 1: Profile of Patients.

Note: SIMD= Scottish index of multiple deprivation with scores from 1 (most deprived) to 5 (least deprived)

Over this period of time, the beds were occupied on 381 days out of a possible 880 bed days. This equates to the five beds having an occupancy rate of 43.3%.

Graph 1 displays bed days occupied per month alongside a line graph displaying the percentage trend of occupancy month on month. As can be seen, the occupancy of the beds fluctuated month on month with a peak of 55% bed day occupancy in March 2022. The dotted line represents the trend line throughout the evaluation period and this displays a general increase in bed days.



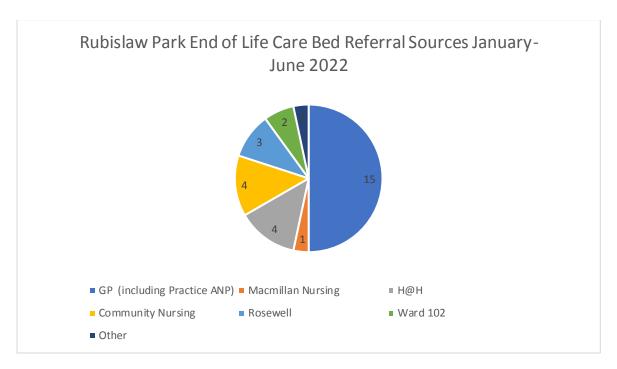
Graph 1: Bed Day occupancy by month. Total number and percentage.

All patients were residents of Aberdeen, apart from one who was transported from Blairgowrie. Looking at the geographic spread of patients and the GP Practices they were registered with, the service accommodated patients from across Aberdeen City. This is also implied from the SIMD data of the patients as displayed in Table 1 which shows that patients were referred from an equal balance of deprived and non-deprived addresses in Aberdeen City.



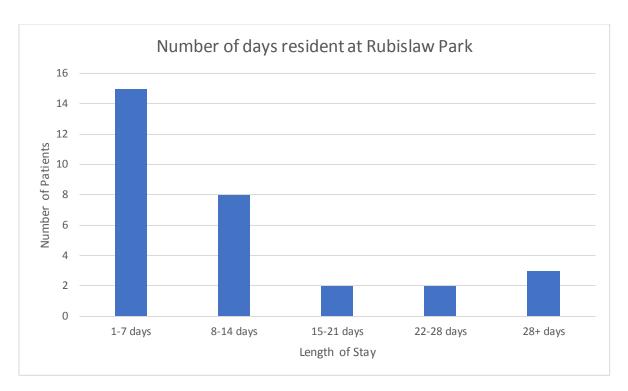
Graph 2: Patient Referrals by GP Practice

Table three demonstrates that half of patients were referred from their GP Practice. Many with input from community nursing. The pathway opened for referrals to be received from Rosewell and Ward 102 in May 2022.



Graph 3: Sources of referrals received by Rubislaw Park for End-of-Life Care beds.

Looking at patient's length of stay, half of those who were accepted for care at Rubislaw Park were resident for a week or less. The average length of stay was 12.7 days. This appears to be in line with the referring PPS score in Table 1 of 31% which would demonstrate low functional status and indicate patients referred to the service are appropriate for end-of-life care.



Graph 4: Number of days patients were resident at Rubislaw Park

3.2 Next of Kin and Carer Survey Results

The next of kin or Carer for fifteen of the patients who were cared for at Rubislaw Park were contacted by telephone and asked to take part in an evaluation. Of those contacted, eight consented and completed the questionnaire. Six interviews were carried out by the Evaluation Team over the phone, while a further two of the respondents chose to complete an online form. A full excerpt of responses from the next of kin survey can be found in Appendix 1.

The following displays the results from the survey which was conducted by the next of kin or Carer. These have been displayed according to the themes which were identified as part of the thematic analysis conducted. Below we have an indication of the quantitative results derived from the survey and some of the general comments received regarding the service.

Question	Respondents answer and percentage.
Do you feel their needs were fully met during their stay?	Yes- 88% No- 13%
Were you involved with their care as much as you would have liked?	Yes- 100% No- 0%
For those who find themselves in a similar position, would you recommend the service?	Yes-88% No-13%

Table 2: Next of Kin Quantitative Survey Results

3.2.1 Referral and Palliative Care provision.

The respondents were asked to provide an overview of how the patient came to need the services of Rubislaw Park. All respondents referenced a deterioration in condition combined with the support network being unable to cope with the level of care required.

Respondent number	Primary Reason for admission.
1	Lack of Support at Home to continue care
1	Lack of Support at Frome to continue care
2	Patient deteriorated quickly and couldn't care for herself.
	Deterioration in the condition at home. Needed personal care that both felt
3	increasingly uncomfortable and challenging to provide.
4	Challenging to support at home once the patient's needs increased.
_	The patient stayed at home as long as possible. The patient had a real fear of
5	needles and hospitals.

[&]quot;It's a great service, and I would be disappointed if it were to stop".

[&]quot;The idea of the palliative care beds are brilliant"

[&]quot;It was a huge relief for us all to know that he was being cared for by the team at Rubislaw Park, as it wasn't safe for him to still be at home"

6	High level of palliative care required
7	Health Declined Rapidly and required additional care that we couldn't provide
8	Increasing levels of unconsciousness and the carer was finding it hard to deal with. Patient would not have wanted to go into an acute clinical setting for care.

Table 3: Primary Reasons for referrals to Rubislaw Park EoL patients, as identified by Next of Kin.

3.2.2 Impact on the Next of Kin

While the physical, emotional and spiritual needs and care of the patient was of primary importance, the respondents identified several different areas whereby the service had a positive impact on their wellbeing and not just that of the patient.

"Initially we were upset [when the patient was referred to Rubislaw Park], but there was an element of relief. We had cared for them both [next of kin's parents] for 2 years and we were exhausted."

"It allowed me to go about life as normal without...attending to [the patient]."

"A huge relief to know that [the patient] was getting round the clock care by health care professionals"

3.2.3 Service Provision and Staffing

The respondents to the survey gave generally positive reviews of the staff which they had encountered at Rubislaw Park. One respondent said, "Everyone there was a 'true carer' rather than going through the motions", while another stated "[the staff were] very caring and accommodating, nothing was a problem".

There were some concerns raised regarding communication and clarity around medication and when it would be received, however others commented that "For the first two days I found it difficult to let go and my main concern was pain relief. By the third day I could see that they had it in hand".

3.2.4 Rubislaw Park Environment

Comments which were received regarding the facilities in Rubislaw Park were generally positive. For example, one respondent commented on how her friend "didn't want a clinical environment" and that "the staff were professional and caring rather than clinical".

Another respondent commented "the location of the palliative care beds within Rubislaw Park were in amongst the general rooms and often overheard staff members and service users... [I was] delighted that staff were happy at their work, however a more subdued area may have been more appropriate.", conversely another respondent found these aspects of the environment comforting "other people at Rubislaw Park were going about their day-to-day routine, very homely, and the dog was lovely".

3.2.5 Processes and Regulations.

Several comments were received regarding the Covid-19 regulations that were in place at Rubislaw Park and some concerns were raised by one respondent that there were inconsistences on how some of the Covid Regulations were followed depending on the whether it was a weekday or weekend. The Covid regulations were in place for the whole Care Home and these in general were out with the control of the project, however many found these to be needlessly complicated. "We supported and followed the strict Covid Guidelines required of us by the Care home and the associated paperwork forms, however we did have some difficulty in filling in these forms".

Finally, some comments were received regarding access to the facility and the entrance not always being manned "[there was] nobody there to meet us when we got there [it was] quite traumatic having to wait".

3.3 Rubislaw Park Staff Focus Group

On 25th April 2022, three of the Rubislaw Park team who worked closely with the patients who use the palliative care facility took part in a focus group. The results are outlined below and are presented as either a benefit, drawback, relating to the general experience and processes and whether there were any recommendations the service would make going forward it the service was to continue.

3.3.1 General Feedback and Benefits

Overall, the Rubislaw Park team reported that they had enjoyed the experience of taking part in the test of change and felt that it had made a difference to the patients and their next of kin/carer's lives and experience of death and dying. They felt that they were able to provide a service which was "tailored to the needs of their patients" while also helping the family or carer to fulfil their supportive role to the patient without having to worry about administering nursing or personal care, unless they wanted to.

The team at Rubislaw Park commented on how fundamental the relationship with the H@H team had been throughout the test of change. To start with there had been continuous communication between the two services and it was felt that as the relationship had developed and trust had been gained around their practices and experience that this had reduced to a manageable level for both teams.

"Interaction with the Hospital at Home team have been great, they are on the ball and responsive to our needs"

"Hospital at Home used to come out every day, but now its probably once a week unless needed or a new patient is admitted, its very positive"

The respondents felt that the service was professionally fulfilling for the team as they are already specialists in End-of-Life care. The impact of the service was also discussed in relation to Community Nursing and it was hoped that it would result in a decrease in unscheduled call outs for Community Nursing to administer break through medication and positively impact on acute admission avoidance. For the patient this would result in the removal of unnecessary delays in receiving medication.

There was general agreement from the team that they would wish for the service to continue.

3.3.2 Experience of the Referral Pathway and the associated Business Processes.

Some of the feedback generated from the focus group centred around how the participants experienced the referral pathway and the related business processes which were put in place throughout the patients stay.

The Rubislaw Park team cited frustration at the challenges around the referral process and communication. The decision for a patient to be removed from their home for end-of-life care can often be a stressful and emotional time for all involved and it was felt that there were sometimes unrealistic expectations from the family members that could have been better managed by ensuring that information packs were disseminated prior to arrival at Rubislaw Park. "[The] patient's family had no idea what to expect, they were very derogatory about the service thinking it was a dementia unit and the patient didn't come in with any meds. We had to work hard to turn it around from there...we got a thank you card afterwards"

There appeared to be occasional inappropriate referrals made to the service where a patient did not necessarily meet the criteria and they suspected that had these patient's been admitted that they would have required longer term nursing needs rather than end-of-life care. It was commented that during the test of change, there had been a high level of scrutiny and communication around referrals, and this would need to continue to ensure that only those who genuinely required end of life care were accepted into the facility.

Once patients had been accepted into the service, there seemed to be some confusion regarding the referrer responsibilities and who was required to arrange transport for the patient, ensure that medication was present and that a Covid test was completed prior to admission. This seems to have added unnecessary stress to both the staff, patient and their next of kin. The service commented that admissions from Rosewell House can be particularly complex.

3.3.3 Drawbacks and Limitations

Since the team at Rubislaw Park are a third party, they do not have access to any of the clinical systems (e.g. Trakcare) to record or verify any patient information. This means that they are reliant on either the H@H team, GP or the family to provide information relating to the patient and their past medical history and ongoing needs if it has not been recorded as part of the referral process. There is also reliance on the H@H team for prescribing and this relies on the H@H team being able to act upon requests in a timely manner.

Finally, many of the concerns raised by Rubislaw Park were acknowledged as 'coming with the territory' of with dealing with end-of-life patients and as a result staff members could sometimes be used as a "natural punchbag for families" for perceived failings of care prior to admission to Rubislaw Park.

3.3.4 Future recommendations

The staff at Rubislaw Park stated that they would like to see the service continue as they believe that it makes a substantial difference to the patient and to their families and "Allows family to be family again". Two recommendations were made by the Rubislaw Park staff who were interviewed as to how the service could be improved:

- The information packs are to be provided to patients/Next of Kin and Carers prior to admission. It was believed that this would help to alleviate some of the unrealistic expectations experienced.
- H@H team screen referrals and thereafter pass these to Rubislaw Park to discuss the
 patient directly with the referrer. H@H would provide referral decision making
 support if required.

3.4 Hospital at Home (H@H) Feedback

Selected members of the H@H team were sent a Microsoft Form to submit feedback, four members of staff responded. Table 4 gives an overview of these results.

	Respondents answer and
Question	percentage.
	Agree-75%
The Referral Process to access the End-of-Life Care beds at	Disagree-25%
Rubislaw Park is easy to follow	
	Strongly Agree- 75%
	Neither Agree or Disagree-
	25%
The Staff at Rubislaw Park are easy to work with	
	Strongly Agree- 75%
	Neither Agree or Disagree-
	25%
The Rubislaw Park team communicate well with my team	
	Strongly Agree - 75%
The patients are well cared for and supported	Not applicable - 25%

Table 4: Overview of H@H survey results

The H@H team were also asked what they believe the benefits are of having the End-of-Life Care beds at Rubislaw Park. The following shows some of the responses received:

"Beneficial to those who are alone, or have no support, or have family/friends unable to provide support for final days of life. Allows family and friends to leave the carer role and have the family/friend relationship. It's a good service!"

"Patients are cared for in a safe environment which can reduce the mental and physical distress and discomfort of the patient and family - allowing them to spend time together in their final period of life.

Rubislaw provides a higher level of care than they can receive at home but still maintains a comfortable homely environment."

When asked about areas about the service that could be improved, the comments largely centred around the referral process. One respondent suggested that the H@H team be removed from the management of patients, suggesting that this may sit better with Community Nursing. While another respondent commented upon that some of the unnecessary delays around the referral process could be due to ambulances/patient transport not being booked and Covid testing swabs not being undertaken in a timely manner.

When asked to rate their experience working with the Rubislaw Park team, respondent averaged 9 out of 10 (where 10 was the best). And one respondent commented that

"The team at Rubislaw are excellent, motivated, caring and professional at all times"



9.00 Average Rating

3.5 Referrer Feedback

As part of the evaluation process, we contacted other services who may refer into the Rubislaw Park End of Life Care Service or who may have continue to have contact with the patients during their stay. We collected responses for GP Practices (3 respondents), Acute referrers from Ward 102 and AMIA (2) and Macmillan Nursing (1). The results in Table 5 show the overall feedback from this group.

Question	Respondents answer and percentage.
The Referral Process to access the End-of-Life Care beds at Rubislaw Park is easy to follow	Strongly Agree- 20% Agree- 60% Disagree- 20%
The Staff at Rubislaw Park are easy to work with	Strongly Agree- 20% Agree- 40% Neither Agree or Disagree- 40%
The Rubislaw Park team communicate well with my team	Strongly Agree- 20% Agree- 40% Neither Agree or Disagree- 20% Disagree- 20%
The patients are well cared for and supported	Strongly Agree- 80% Neither Agree or Disagree- 25%

Table 5: Overview of Staff group's survey results.

"A really useful resource and they have provided excellent care for several of our palliative patients with the help of the H@H team also. Feedback from relatives has been universally positive. A useful additional resource to Roxburgh and essential for our increasingly frail elderly population where access to social care can be very difficult." And that

"I think this has been a fantastic initiative and should be continued if not expanded!"

"An excellent facility, much needed in the community. Found to be best place of care for end of life for those patients known to our Macmillan team who have been admitted."

4. Discussion

By utilising the original questions and statements set out in section 2.2, the results can be discussed and assessed whether these have been met to a satisfactory level.

4.1 Understand the realised benefits for patients, next of kin/carers and staff.

This section is broken down into the benefits highlighted throughout the evaluation pertaining to each perspective.

4.1.1 Patient Perspective.

The project set out to provide an equitable service for the whole of Aberdeen City. The SIMD data provided in Table 1 and the spread of GP Practices found in Graph 2 appears to support this. As can be seen in Table 2, we can conclude that on the whole the largest proportion of respondents indicated that the needs of the patients were fully met and comments supplied by the Next of Kin appears to support this with many suggesting that the patient was relaxed and peaceful after admission with the knowledge that someone would be there throughout the day and night and that they would not be alone. This supports the notion of an increase in care to a 24/7 service compared with a community service input while the patient was cared for in their home.

Looking at Table 3 regarding the primary reason for referral, the Next of Kin has identified that it is the combination of increased nursing care and decreased ability from the Next of Kin to provide this which led to the patient's admission. This appears to be in line with the intention of the service to provide a service for patients who required increased nursing care which their next of kin was unable to support them with and therefore were unable to continue being cared for at home. This information may also be useful going forward for promotion of the service to patients, their next of kin and to colleagues.

4.1.2 Staff perspective

Looking at the results in Table 4 and 5, we can see that from those who responded, 80% of staff and 75% of H@H staff believe that patients were well cared for and supported. There also appears to be evidence from the feedback received that the service can "reduce the mental and physical and distress and discomfort of the patient and family, allowing them to spend time together".

4.1.3 Next of Kin/Carer Perspective

The Next of Kin/Carers who were approached appear to feel well supported in their role and as Table 2 shows, 100% of respondents said that they were involved with their care as much as they would like. Respondents also demonstrated the impact that the support of the

Rubislaw Park team had on enabling them to resume their role as family member or friend with many mentioning an element of relief upon admission.

There were some concerns raised around the building facilities and location of the beds. Some of these comments were regarding Covid 19 restrictions, and although these have been taken on board, it would be hoped that these are not longstanding due to the continuing lifting of many restrictions. Other comments regarding the location of the rooms within Rubislaw Park are a little more difficult to act upon. The rooms are near each other, but Rubislaw Park are unable to provide a separate wing of the building for only this purpose therefore even if the rooms were moved to a different area, the care home, its staff and residents would still be part of the environment.

Ultimately, 85% of respondents agreed that they would recommend the service to others that found themselves in a similar situation and The Hospital at Home team also rated the experience of working with the Rubislaw Park team as 9 out of 10.

4.2 Understand whether the service is managed in an effective manner, regarding the business processes, communication etc.

From the feedback provided as part of the evaluation, three main themes appeared:

- 1. Communication
- 2. Referral Pathway
- 3. Bed Base Occupancy

Each of these will be discussed in turn.

4.2.1 Communication

The concerns raised regarding communication relates to external communications with the patient and Next of Kin about the service. It was suggested that further communication from the outset may have helped manage the expectations of the service. There could be a variety of reasons for this, such as being a newly established service and other staff's uncertainty about what the service provides or where to locate the pertinent Patient Information Leaflet to pass across to patient's and their Next of Kin/carers. Certainly, if the service was to continue, a robust Communications Plan would require to be formulated in order to ensure that the effect on this on the service could be reduced.

4.2.2 Referral Pathway

In line with the introduction of a new referral pathway, there were several challenges highlighted from the feedback received. Some carers and next of kin raised the challenges of getting referred, or only particular people being aware of the service. The Rubislaw Park and H@H teams mentioned the uncertainty and impact upon referral and admission of who was responsible for providing patient transport, medication and Covid testing. Feedback from the Macmillan team added that changes to the referral protocol in May when it was opened up to Ward 102 and AMIA may have added to this confusion. Despite these challenges, it appears that the referral pathway in place and the rigorous process in place from the H@H team appears to have assisted in ensuring that the service is used only by those who are effectively in the last few days of life. This is demonstrated by the PPS score in Table 1 and the Length of Stay in Graph 3. Interestingly, the average length of stay is 12.7 days which is also in line with the average Length of Stay in Roxburghe House in 2021 (Roxburghe House is a specialist palliative care unit in Aberdeen) the similarity of the figures here help to demonstrate the appropriateness of the referrals received.

In order for the service to continue or expand, the referral protocol should be reviewed and effectively communicated to referrers and their teams in order to gain clarity over the situation. Risks over service provision where key members of staff are on leave or leave employment should also be taken into consideration so that consistency of care and referral pathways can be assured.

4.2.3 Bed Base Capacity

In Graph 1, the occupied bed base figures per month are displayed with an average of 43.3% occupancy over the evaluation period. There were occasions where all five beds were in use. Prior to the service commencing, there was no real indication on what the need for the service would be. We can see that there is a general upward trend in Graph 1 so it may be the case that the complications over the referral pathway is having an impact on those referred, or that there is still some uncertainty as to who the referral pathway is available for and that this is having an impact on the occupancy levels. If a decision was taken to open these beds to other patients who are not end-of-life, then there would be a risk of patients who have longer term continuing care needs utilising the provision and there would be an inability for those genuinely in need of the service to access it.

Looking at the population data for Aberdeen City, as outlined in the introduction to this evaluation, the need for palliative care support across the city is likely to increase over the next two decades. It was suggested by feedback provided by GP practices that the service should be opened to other acute services rather than only Ward 102, AMIA and Rosewell. This may increase the bed base occupancy rates and give a true reflection of the service need while also reserving these beds for those truly in need of the service. Optimal Bed Base occupancy is generally considered to be between 80-85%, however some literature points towards 45% for smaller hospitals (Ravagi et al, 2020), so it may be the case that the

Steering Group need to review the occupancy levels and consider what is appropriate for the service and for the delivery teams involved.

4.3 An assessment and recommendation regarding the future provision of the service

The population projections outlined in the introduction demonstrates that in order to meet our future needs, there is a need to look at options for end-of-life care that is outside of the traditional models of either home or hospital. The evaluation of the Rubislaw Park service looked to ascertain whether this model met its original intentions, and whether a recommendation could be made to continue the service.

From the information collected for this evaluation, it can be concluded that the service met the needs of the patients and their next of kin/carer's, and on this basis it is recommended that the service is to continue. However, it was also expected that the service would have an impact upon admission avoidance, and that it would lessen the impact on community services with regards to unscheduled call outs to give breakthrough medication etc. While this is likely the case, it has been challenging to obtain and make judgement on the service's impact upon these areas. This has been due to the small numbers involved in the service up to this point and the difficulty in obtaining data which can truly reflect the impact upon community services. Going forward, it would be beneficial to take this into account so that data can be collected and measured on these factors to make this assessment more robust.

5. Conclusions and Recommendations

The evaluation of the Rubislaw Park end-of-life care beds has highlighted the positive impact that the service has had on the patient and their next of kin/carer's wellbeing. Staff and the patient's next of kin confirmed that it allows them to resume the role of family or friend rather than the primary care giver and as such provide an important emotional role to the patient as part of their end-of-life Care.

The evaluation concludes that the service provision at Rubislaw Park appears to satisfy its original intention to provide a service to those patients who have increased end-of-life care needs beyond the capacity for their support network to provide but does not require specialist intervention. The evaluation has also found that in order for the service to continue its success and to operate at capacity that a number of recommendations are being made:

- 1. Attention to the environment surrounding the End-of-Life beds should be assessed, for example whether the beds could be located in a separate area or separated from the general goings on of the larger care home environment.
- 2. The Referral Pathway should be scaled up to allow referrals from all acute services to ensure that the bed base occupancy is fully utilised to an appropriate level while also ensuring that continuity of care from the Rubislaw Park and H@H team can continue.
- 3. Communications Plan requires to be reviewed. Work to enhance the current level of communication needs to take place, including
 - a. Publicising the service,
 - b. Setting expectations for patients, their family members and/or carers.
 - c. Internal communications between services regarding the referral processes and for those admitting patients, what needs to be in place (for example transport, medication etc upon arrival.)
- 4. A further evaluation should be conducted 18months after the scaled up service is established. This would allow for bed base occupancy trends to be reviewed and monitored over a period of time. The impact on the Community Teams (Community Nursing, social work etc) should also be reviewed as part of this further evaluation alongside an assessment on admission avoidance.

Finally, based upon this evaluation and its recommendations, a business case should be developed and presented to the Aberdeen City Integration Joint Board outlining the case for the service to continue.

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Appendix 1- Next of Kin/Carer Feedback

The following displays the qualitative next of kin or Carer feedback received as part of the evaluation. The feedback collected as part of the evaluation was done so anonymously, so where any ambiguity remains in the feedback, this has changed to nongender specific referencing where appropriate to ensure that anonymity remains. Any added text which has been added to increase readability has been surrounded by brackets []. On a couple of occasions, text has been redacted completely where a patient's specific diagnosis was discussed or where specifics regarding a patient has been mentioned which may jeopardise their anonymity.

Tell me about your experience and interactions with Rubislaw Park?		
1	I can't really fault it. Staff were really good. One concern continuity at the door - not checking if you did your covid test. Constantly had telephone to get someone down from the ward to come down. Continuity at front of house would be helpful. No continuity in terms of PPE what they had to wear.	
_	[Patient] went in on Tuesday and died on Thursday. The two nurses who we seen were	
	very nice are caring and said that it was a pity they didn't get a chance to know her better. Nothing was ever a problem for them and all the staff were very polite.	
2		
	Very good interactions with all staff. [The patient] was in for 2 weeks	
3		
	Everyone was lovely	
4		
	taken in on Saturday after [the patient] was set up with a Morphine Pump on Thursday. Initially staff were brilliant. However, went up on Sunday and we didn't see anyone, [the patient] was very agitated. It took the staff 20minutes to answer the buzzer and 40 mins to come back with break through meds. On Monday [the patient] was agitated again and although [the patient] was drugged up [the patient] knew they needed the toilet and was trying to get up. The nurse came in and said that [the patient] was wearing a pad and that [the patient] could just let it go. In the end [the patient's family] helped [the patient] use a bed pan. no one came to see if the pad needed changed. [The patient] died on Tuesday and the nurse that day was	
5	brilliant and very attentive.	
6	Our experience was very good with all concerned at Rubislaw especially how Fiona and her team dealt with the situation.	
	As a family we had both positive and negative experiences / interactions with the Rubislaw Park team. [The patient] was picked up by Ambulance patient's] home, it was the morning of and there was a lot of snow,	
-	making it difficult for driving. I realised that they hadn't taken his emergency	
7	medication that had been issued the day before including the sedative Midazolam	

with [the patient]. I phoned the care home, they said they would greatly appreciate it, if we could drop it off. Which we did, we didn't visit dad that day.

I then got a phone call from the Care Home asking if we could bring in all his other prescribed medication including medication including following day (Saturday).

On our first visit on Saturday 19th February, we were surprised to see a can of coke, a cookie and a glass of orange juice on dad's tray table. [The patient] had an extensive oropharyngeal carcinoma and had difficulty swallowing, [the patient] had stopped eating food earlier in the week, and we wondered if the staff were fully aware of [the patient's] condition.

[The patient] was tossing and turning in [their] bed trying to sleep during our visit, but was laying very close to the edge, [the patient's family] who was visiting, informed the duty RGN [nurse] that [they] were worried [the patient] would fall out of the bed. [the nurse] came into the room put on the light and in a loud voice she asked [the patient] to move over the bed which disturbed [the patient]. Later that evening, I received a phone call from [the nurse] to say that [the patient] had fallen out of bed. [the nurse] said that they didn't want to put the sides of the bed up, in case [the patient] got [their] leg stuck through it.

We all followed the Covid Protocol as required by Rubislaw Park Care Home, [the patients family] was asked to fill in a set of 4 forms for [their] visit. It was a pleasant visit. [The patient] had been shaved and although very tired, [the patient] did communicate with us for a short while. We brought in some straws to enable [the patient] to drink and also [the patient's] supply of drinks. [The patients family] handed them over to the duty RGN and asked her what medication he was getting and was told [the patient] was getting no mention of drinks asked her what anything else.

On Monday 21st February, [the patient's family] phoned Rubislaw Park and spoke with the care home manager to check with her that [the patient] was definitely in for Palliative Care and not Respite Care. [The patients family] was assured that he was in for Palliative Care and that the staff would know when the time was right to administer.

[The patients family] informed the manager that she would be visiting dad later on in the afternoon.

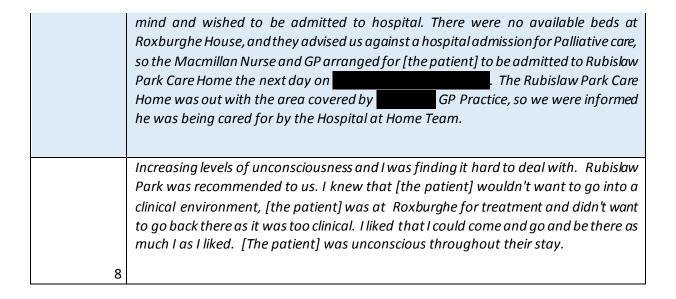
When they arrived at Rubislaw Park Care Home, they were asked to wait outside in the cold by the receptionist while other visitors complete the required paperwork forms. There was an issue in filling out the forms and [a family member] who has dementia, has very little patience and was moaning about the time it was taking. [A patients family member] was taken aside by the manager and given a bit of a talking to in her office.

[The patient] was very poorly, it was a very distressing visit for them both.

On Tuesday 22nd February, I got a call @ 8.10 am from [the nurse] RGN to say [the patient] had taken a turn for the worse and we should get there ASAP, I then got another call from her to say [the patient] passed away @ 8.56am.

	We arrived at 11.30am to say our final goodbyes, again we filled out the required paperwork forms, pretty dismayed that we were given the "The Visitor Feedback Form" to fill in even although we'd told the receptionist that our [family member] had died. [The nurse] was very kind to us and showed us to [the patient's] room, we were taken aback to see him lying there with [their] eyes and mouth open, again it was very distressing, we didn't expect that. We packed up all [the patients] things there and then and left. The care assistants were extremely pleasant and helpful.
8	First impression was that it was a homely environment that was really friendly. The staff were efficient, professional and friendly. [The patient] had a quick admission which we were really grateful for.

What led to th	eir admission to Rubislaw Park rather than being cared for at home?
	Husband died during covid. No family. Diagnosed with cancer pre christmas, battle with care management to get her into care. No availability for care at home. Very grateful for care @ home. No receipt of care before that - in sheltered housing before that through Bon Accord Care.
1	Patient deteriorated quickly and couldn't care for herself and kept falling out of bed
	[The patient] dreaded going to sleep as [the patient] was by herself. Seemed like [the patient] relaxed once she went into Rubislaw Park and went to sleep.
2	
	Deterioration in the condition at home. Needed personal care that both felt increasingly uncomfortable and challenging to provide.
3	
	[The patient's spouse] died 16weeks before [The patient]. [The patient] had their lung drained regularly but quite quickly went downhill after [The patient's spouse] died and took to [their] bed. Thereafter needed a lot of personal care. Was already in sheltered housing. [another family member] went to Rosewell unit and expected Rubislaw to be a similar place and for him to get more medical attention to build him up again.
4	
	[The patient] stayed at home as long as possible. [The patient] had a real fear of needles and hospitals. [The patient] was also an alcoholic.
5	
	[The patient] required a high level of palliative care which Rubislaw were well placed to provide.
6	
7	[The patient's] health declined rapidly in [the patient's] last week of life and although [the patient] had originally stated that [they] wanted to be cared for at home, [the patient] became so weak, and was unable to walk that [the patient] changed [their]



Please add any further comments (relating to whether their needs were fully met during their stay).		
	[The patient] said they were lovely "more than accommodating than what [the patient] wanted"	
1		
	[The patient's] admission allowed [the patient] to relax in a way [they] couldn't at home.	
2		
	From a nursing perspective, always seemed that [the patient's] needs were met. We were there every day from 9am-evening and always attentive	
3		
4	Only drained lung once which was a surprise, however not a complaint just wasn't sure why it wasn't done more often	
5	We didn't feel that [the patient] had dignity up until the end. We considered supplying feedback but just wanted to draw a line under it	
	The main purpose of keeping [the patient] comfortable and pain free was achieved throughout [the patient's] final days.	
6		
7	Found it difficult to answer yes but couldn't answer no as unsure what other care /treatment he could have been offered	
8	Asked if there was anything more they could do or I would want to do. For the first two days I found it difficult to let go and my main concern was pain relief. By the third day I could see that they had it in hand	

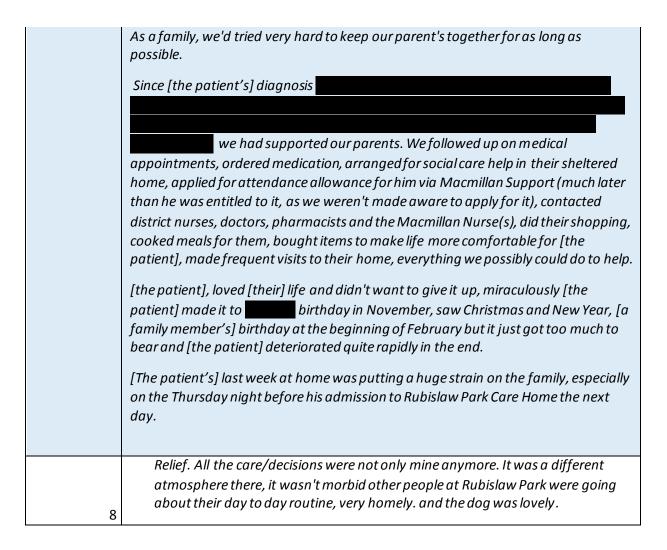
What do you think they valued the most about the support the Rubislaw Park team provided?

	the staff - very attentive. originally questioned whether [the patient] made the right decision but thought it feels quite nice.
1	
	Knowing there was someone there during the night.
2	
	Overnight personal care
3	
	[The patient] was an easy going character and they treated [the patient] as a person. Everyone there was a 'true carer' rather than going through the motions.
4	
	[The patient] was terrified of dying on [their] own so it provided comfort that there was someone near by at all times. It was also a more comfortable surrounding for us as [the patient] had sold a lot of his belongings.
5	
	Because of [the patient's] condition [the patient] probably couldn't appreciate the care [they were] getting although it was clear to us.
6	
	[The patient] realised that [they] couldn't be cared for at home as [a family member] has multiple health issues and was unable to look after [the patient] at home. It was very distressing for them both. On [the patient's] last evening spent in their home, as [the patient] had been catheterised and kept trying to get up to the toilet and ended up falling several times. [The patient] would have valued having round the clock care, professionals on hand to help [them] and not be causing [another family member] any further worry.
7	
	The staff were professional and caring rather than clinical. [The patient] didn't want a clinical environment.
8	

Please add any further comments (about whether you were involved in their care as much as you would have liked).		
	Had doubts originally about [the patient] going in, had some negative feedback originally. staff very welcoming.	
1		
2	we had lots of contact with the team	
	Allowed to be involved as much as we liked. Made clear by [the nurse] who asked a few times whether there was anything else we would like to do	
3		

	Lateral flow on admission was a little frustrating as just wanted to get in and see [the patient]
4	
_	Had more involvement than perhaps wanted at times. The nurse on Sunday was very respectful towards us and him at the end
5	
	The team were always receptive to my requests if I felt was requiring further medication to ease pain and they would take time out to explain various points regards treatment.
6	
7	No Comment Made
	I still felt in charge and involved
8	

How did their	admission to Rubislaw Park impact on you?
	negative initially because [the patient] didnt want [them] to go in. changed when [the patient] met the care staff, very caring and accommodating, nothing was a problem. "cant fault them"
1	
	It was a relief that [the patient] had someone there 24/7
2	
3	Positive impact. We had a system at home where [the patient] would call through if [they] needed my help, however i often felt a dread on what I would find. Increasingly both felt uncomfortable at providing personal care. We were aware that there would be an increased time dependency on us travelling to see [the patient] at Rubislaw Park, however happy to take that decision so that [the patient's] needs could be met
	Initially we were upset, but there was an element of relief. We had cared for them
	both for 2 years and were exhausted.
4	
	Relief to us to have someone there.
5	
	It allowed me to go about life as normal without the added burden to attending to [my family member].
6	
7	[the patient] was only in Rubislaw Park Care Home for 4 days, so it didn't have much of an impact on my health and well being apart from it being a huge relief to know that [the patient] was getting round the clock care by health care professionals. We had come to the conclusion that [the patient] couldn't continue being looked after at home, it just wasn't feasible anymore.



How do you think the service could be improved?		
1	only allowed one visitor. feedback about needing to change before going to visit (was wearing care equipment).	
2	The patient was there for 2 days, so not sure it was enough time to really comment on anything	
3	It took a lot to try and get [the patient] into palliative care facility and the DN needed to be quite forceful in order for [the patient] to be taken in, although understand that other facilities (e.g. roxburghe) were full at the time. It was a very stressful time for the whole family.	
4	[the patient] was there a week, so don't think we were there long enough to comment on anything	
5	Overall great service. Staff had their hands full and the general environment was great	
6	Very difficult to say how it could be improved as it appeared faultless to us.	

Patient safety is a concern and I certainly think better communication from the Nursing staff to the family would help improve the service.

To hear that [the patient] fell out of [their] bed on the Saturday evening after [a family member] had flagged it up with the RGN as a potential issue, was not satisfactory. If permission from the family was needed to raise the sides of the his bed to prevent this, why was it not asked for on the Saturday?, when it was asked for on the Monday by another RGN. The reception staff might benefit from some training in how to deal with family visiting Palliative Care patients. We didn't feel it was appropriate to be given a visitor feedback form to fill in, on the morning [the patient] had died when we had already informed her that he had just passed away. Of course we supported and followed the strict Covid Guidelines required of us by the Care home and the associated paperwork forms, however we did have some difficulty in filling in these forms.

The first 2 forms were very straightforward, visitor details, name address, contact telephone number, tick box Yes/No answers and a box to record your temperature reading taken from the digital thermometer at the entrance. The third form headed with ??GCC Logo was poorly set out and difficult to know how to answer some of the statement/questions. There was a small box at the LHS of the each statement/question, was unsure if we had to tick it or write a response. We asked the receptionist for some guidance as to what was expected and she asked another member of staff, who told us it was mandatory for us to fill it in. Not very helpful. We weren't refusing to fill it in, just wanted some guidance. Staff could possibly benefit from some training in helping visitors fill in forms.

The fourth form was the visitor feed back form. The last issue, would be, continuity concerning face coverings and hand sanitising. Saturday Visit - Entered the reception area and into the main care home accompanied by the duty RGN, wearing a face covering, sanitised hands using the alcohol gel provided.

Sunday Visit - same as above

Monday Visit - The visitors were told by the receptionist and manager to go to the toilet, take off their old masks, wash their hands, put on fresh masks and then sanitise their hands. If Monday's procedure is the correct method, then the weekend staff should also insist that visitors follow that.

7

nothing I can think of

8

Do you have any other comments you would like to make? nobody there to meet us when we got there - quite traumatic having to wait. the staff there genuinely did care and didnt just go through the motions. Going in the door there wasn't always someone there, however wasn't a big issue, it just meant waiting a couple minutes

3	Nothing additional to add
4	[The patient] was there a week, so dont think we were there long enough to comment on anything else
5	The idea of the palliative care beds are brilliant. Only found out about these from his care worker. However, we were disappointed in how they attended to [the patient's] personal care.
6	Our first contact was [a nurse] and she gave us comfort from outset that my mother would receive excellent care in her final day. All the team were very obliging when we visited and presented a friendly and concerning image which again helped us through this sad period.
7	It was a huge relief for us all to know that [the patient] was being cared for by the team at Rubislaw Park, as it wasn't safe for [the patient] to still be at home. However we did expect [the patient] to be a bit more sedated / comfortable than [they] were on our visits, [the patient] was very restless on the Saturday, and on the Sunday [the patient] was saying [they] had a sore belly, we didn't expect [the patient] to be complaining of any pain whatsoever.
,	It's a great service, and I would be disappointed if it were to stop.
7 8	team at Rubislaw Park, as it wasn't safe for [the patient] to still be at home. However we did expect [the patient] to be a bit more sedated / comfortable than [they] were on our visits, [the patient] was very restless on the Saturday, and on the Sunday [the patient] was saying [they] had a sore belly, we didn't expect [the patient] to be complaining of any pain whatsoever.