



"It takes a minute to feedback, but the difference could last a lifetime"



Contents

Executive Summary	3
Introduction	5
1.Methodology	7
2.Observations and Findings	8
Carers	8
Choice of care agency	9
The range of activities	9
Access to health and social care services	10
A split between those people who receive care and support and those that	
Accommodation.	12
The best thing about living in extra care	12
What could improve	14
3.Discharge from hospital	15
4.Action points - to inform discussions with providers and commissioners	17
Contact us	18
Disclaimer	18
Appendix 1 - Healthwatch East Sussex enter and view programme for extra c facilities: prompt sheet/ questionnaire for residents/tenants	
Appendix 2 - Healthwatch East Sussex enter and view programme for extra care facilities: questionnaire for care managers	

Appendix 3 Healthwatch East Sussex enter and view programme for extra care facilities: prompt sheet/questionnaire for tenants not receiving personal care... 21



Executive Summary

Healthwatch East Sussex visited all extra care services in East Sussex, one as a pilot project in October 2018 and the other seven in March 2019. We met with a total of 101 people who live in the extra care schemes. On all schemes except one, the vast majority of people met with receive some level of care and support. The others did not receive any care.

The visits identified a number of key issues: positive comments about the carers, choice of care agency, the range of activities, access to health and social care services, a split between those people who receive care and support and those that do not, issues about the accommodation.

The view of people receiving care and support was consistently positive about the carers and the quality of care they receive. This was across all eight extra care services.

People told us that they receive the right amount of care and support. They also confirmed that they can ask for this to be increased, or decreased, and believe this would not be a problem. They said they have good access to healthcare services.

Care managers stated that there were sometimes problems with people being discharged from hospital back to the extra care service, primarily because the care service was not informed of their discharge. They felt that hospital staff thought they were a care home, and do not understand that people live in their own accommodation with some support.

Very positive feedback was given about the quality of the care and carers. People told us that they were given a list of who was coming each week, so they knew in advance. They appreciated this. People also told us that they thought they could change the level of support if needed and that this would not be a problem. People were unsure whether they could choose to have their care from an agency other than the in-house one. However, care managers stated that people's tenancy agreements did not insist that they use the in-house care provider.

Most people liked the idea of having activities at their extra care service. These tended to be more organised in those services where there was a residents' committee which led many of the activities and events.

Most people stated that they had good access to healthcare services, particularly where the GP surgery was next door or on the same site as the extra care service.



There were examples where there was a divide between those people who do not need care and those that do. The former often stated that they were not expecting so many people to need care and to such an extent. This could cause some friction and was a particular issue at two services. Care managers were aware of the matter and looking at ways of overcoming them.

The vast majority of people liked their accommodation. A key point was that people felt safe and secure. They were able to maintain their independence whilst having carers on site to assist them when they needed it and also liked having their own front door. In nearly all services there was a sense of community, with people, stating that they liked the company and social aspects of the extra care service.

Where any issues were identified, these were discussed with the care managers. It was good to note that they were already aware of the issues and addressing them.

Care managers reported that there are issues about discharge from hospital. The key issue is that hospitals and those involved in discharge home, thought extra care services were care homes. This resulted in care providers not being told about someone returning home and so found it difficult to resume the care services.

Six Action Points have been made for discussion with commissioners and providers.



Introduction

Healthwatch is the independent consumer champion created to gather and represent the views of the public on issues relating to health and social care. We have a legal footing, as we were created under the Health and Social Care Act 2012. One of our responsibilities is to 'Enter and View' health and social care establishments and services, in order to seek the views and experiences of people receiving a service.

Healthwatch East Sussex has not been involved in any projects to seek the views and experience of people who receive care in their own homes.

A definition of extra care is provided by East Sussex County Council: "Extra care housing is housing for older people with care and support needs who wish to continue to live independently. Round-the-clock care is provided on site. Flats in extra care schemes can either be rented or bought. Everyone living in extra care housing must have an assessed care and support need. Extra care housing can be considered as an alternative to residential care".

By this definition, extra care services can be seen as a step down from residential care. Whilst care is available, people in extra care maintain high levels of independence. They have their own flats and so have their own front door. They will have a tenancy or may have bought the flat, through a shared equity scheme. The latter is where the person buys 75% of the accommodation whilst the landlord retains the other 25%. This means that residents retain control over their immediate environment, including who they allow into their flat.

There are currently eight extra care services in East Sussex.

These are:

- Bentley Grange, Binder Lane, Hailsham
- Cranbrook, Pembury Road, Eastbourne
- Downlands Court, Peacehaven
- Margaret House, Uckfield
- Marlborough House, St Leonards on Sea
- Newington Court, Ticehurst
- St Bartholomew's Court, Rye
- The Orangery, Bexhill

There is a good spread across East Sussex, with the exception of the western side of the county around the Lewes area, although there is an extra care service in Peacehaven.

At seven of the eight services, there is a clear separation between the landlord and the care provider. The landlord is a housing association. The exception is at St Bartholomew's Court, Rye, where the Sanctuary organisation, through slightly separate sub divisions of Sanctuary Housing and Sanctuary Care, provide both the



accommodation and the care. Where what is deemed 'personal care' is provided to people, the provider must be registered with the Care Quality Commission (CQC). All the care providers of these extra care services are registered and therefore must abide by the rules and regulations for care services.

All services had a care manager and a scheme manager. The latter has responsibility for the accommodation.

The CQC document titled 'Housing with Care - Guidance on regulated activities for providers of supported living and extra care housing' 2015, sets out these rules. It states:

"The providers of the care and accommodation are not usually the same legal entity. Even where they are, there is a clear separation between the accommodation and the personal care being provided. There are separate contracts in place for the personal care and accommodation being provided. There is no overarching agreement or contract in place restricting the supported person's choice about who provides their personal care".



1. Methodology

Prior to the Enter and View activity, a visit was made to each service to meet the care manager and explain work of Healthwatch and the purpose of the proposed activity. Notice of the date of the visit and names of Authorised Representatives (referred to Ars throughout this report) was confirmed in writing to the care managers and sent to each flat in the extra care facility. A poster was also put on display at the service. People therefore knew in advance of our visit and had the opportunity to inform the care provider whether they would like to meet with us, or if they would prefer not to.

The focus of the visits was to obtain the views of people who live in extra care services about the support they receive and also about access to health and social care services. A questionnaire/prompt sheet was used to record our conversations with people (appendix 1).

All visits were carried out in March 2019. The exception was Marlborough House, which was visited by two Authorised Representatives (ARs) in October 2018. This was used as a pilot, to test out the methodology, prior to rolling it out to the other seven extra care services. Three Authorised Representatives (ARs) visited each of the seven extra care services. This enabled two ARs to visit people in their flats, with their permission, whilst the other AR stayed in the communal areas, to talk with people there.

The issue of how people who live in extra care are discharged from hospital was also explored. This was raised by one of the care managers during the initial visits, indicating that there are some issues and problems. A questionnaire (appendix 2) was sent to the care managers at the extra care services and all were completed and returned.

A planning meeting was held prior to the visits for all ARs, to prepare for the visits, including going through the methodology and the forms to be used. We identified that some people at the extra care services may not receive any personal care. A separate prompt sheet was devised for those people we met with who do not receive care and support (appendix 3). A debrief meeting was held after all the visits had taken place, to assess the project and to identify what worked well and what did not. We also began to identify some of the themes from the visits.

An individual report has been prepared for each of the services. A draft version was sent to the care manager for each service, so they could identify anything that was factually incorrect. They also had the opportunity to add a response to their report, which was included in the final version. These reports will be available on the Healthwatch East Sussex website, with links to each service.



2. Observations and Findings

We met with a total of 101 people who live in the extra care schemes. At all schemes except one, the vast majority of people met with receive some level of care and support. This was about 75-85% of the total people seen. The others did not receive any care. The exception was at St Bartholomew's Court, where only 23% of the people met with received some level of care and support.

The visits identified a number of key points: positive comments about the carers, choice of care agency, the range of activities, access to health and social care services, a split between those people who receive care and support and those that do not and comments about the accommodation.

"wouldn't want to live anywhere else - 10 years' happiness since I have been here."

Carers

The views of people receiving care and support were consistently positive about the carers and the quality of care they receive. This was across all eight extra care services. This is illustrated by the following comments about the carers below:

- ✓ "they are all very good and friendly" (Newington Court)
- ✓ "very helpful" (Downlands Court)
- ✓ "carers are fantastic, I cannot fault them" (Marlborough House)
- ✓ "fabulous carers" (Bentley Grange)
- ✓ "they're marvellous (Cranbrook)
- ✓ "they are all nice, the management is good" (The Orangery)
- ✓ "I feel comfortable with them" (The Orangery)

Although people told us that they receive care from many carers, sometimes different ones each day, the vast majority of people said this was not an issue. Some liked the idea of seeing different people. The only exception is where services have to utilise agency carers. People told us that they tend to come and go and so are not consistently at the extra care service. This is in comparison to the permanent staff who they get to know very well.

People told us that they receive the right amount of care and support. They also confirmed that they can ask for this to be increased, or decreased, and believe this would not be a problem. For example, one person at St Bartholomew's Court told us that they had a fall and needed additional support for a brief period of time and that this was easy to arrange.

People received a list of carers each week. This meant they knew who was coming and when. People told us that they liked this.



Most people told us that carers arrived on time, give or take a few minutes. They also stated that there were times when carers were running late, usually due to an emergency occurring with another resident. The general feeling was that carers work hard at good time keeping. A few people thought carers were "clock watching" and as a result were a bit rushed. However, this was a minority view.

There was a 50 / 50 response to the question about knowledge of a care plan. This is a document setting out what care and support the person requires, so that carers know what they need to do. This should be reviewed regularly to ensure it continues to be accurate and identify each person's care needs.

Choice of care agency

The vast majority of people told us that they thought they had no choice about where to get their care and support. They felt they had to have the in-house care team. Having said this, people did not see this as a problem, as they received good care. There is also the benefit of the carers being on site 24 hours each day and so available in an emergency. One person at The Orangery stated, "I just accepted what I was offered, and I have nothing to complain about".

One or two people told us that they had a choice and one had chosen an external care provider. They were part of the direct payments system which meant they had their funding for their care and support paid directly to them, so they could decide who they employed to provide care.

Care managers at the extra care services responded to this matter by stating that residents can choose to receive their care from other providers. The tenancy agreement does not state that they must obtain their care from the in-house care provider (or that they can choose).

The range of activities

All extra care services offer a range of activities for residents. The response varied between services with some being more enthusiastic than others. The services with the most activities were those where there is an active residents' committee.

The report for Bentley Grange states the following:

- There is a committee of residents who organise the activities, so they are actively involved in them. Regular fish and chips evenings are arranged. Posters were on display to advertise events. Feedback included:
 - ✓ "something everyday"
 - ✓ "I join in with all the activities"
 - ✓ "something on all the time"

The care manager at Bentley Grange reported: "The residents have worked very hard to get the committee up and running and it is a great success, enabling a lot of residents to join in activities."



We felt that the range of activities could be extended at Cranbrook, following feedback from some people. Their report states "The care manager and scheme manager are aware of this but are not funded to provide activities."

All services had notices of future activities, so residents knew what was happening and when. People met with confirmed that they were aware of the what was being organised. Some made a choice of not getting involved in activities whilst others enjoyed them.

Some services had tried to encourage residents to form a committee or residents' group, but with limited success. St Bartholomew's Court used to have a residents' committee, but this had folded. However, they have been proactive in looking at ways of reducing isolation. The care manager reported; "We have identified some of our clients are lonely and have just implemented a new incentive. We have given all clients door hangers which say on them, I would like to be visited for a chat. Some clients have visited others for social time. This is a client lead scheme. We are also using our activities coordinator to visit people who have expressed a wish to spend time with someone on a one to one basis. This is working well."

The manager at Downlands Court reported that she and the scheme manager meet with the residents' committee on a regular basis and this enables residents to influence what happens at the extra care service.

Access to health and social care services

The vast majority of people told us that they have no problems getting access to health and social care services. Newington Court, at Ticehurst, has the benefit of the GP surgery being next door to the extra care service. Access is possible without leaving the building. A GP surgery is also on the same site at St Bartholomew's Court, Rye.

Some people told us that the care office can assist in making appointments. Where difficulties were identified, this was usually related to problems getting a GP appointment in the same way that this can be a problem for any member of the public.

Most people spoken with said that they have family and friends who can assist them with making appointments as well as getting them there. However, a few people, who do not have this support, said they can find it difficult with transport to appointments.



A split between those people who receive care and support and those that do not

In all extra care services, there are some people who have purchased their flats through a shared equity scheme, as described earlier. Our findings are that these people tend to require very little, if any, care and support. In all but one, St Bartholomew's Court, the number of people who had purchased their flats was relatively low in this review.

There can be different 'rules' about who can move into the extra care scheme. For example, for those people who require some care and support, they need to be at least 60 years of age and be assessed through Adult Social Care. The latter tend to fund the care element of the scheme. There can be a set minimum level of care such as 5 or 10 hours each week. This varies between the extra care services.

For those people who have purchased their flat, they must be at least 55 years of age. They do not need to require any care and support. Feedback from some of this group was that they thought the extra care scheme was for people who were independent but needed a little bit of care. However, they had subsequently found that some people need high levels of support.

This was particularly an issue at St Bartholomew's Court. The report for this service states: "some people said they were told the scheme was more independent living than extra care and so were surprised by the number of people who need care and support, some having an element of dementia."

The report then goes on to state: "From discussions with the Manager, the following conclusions were drawn. The high number of people who do not need care and support may well have created problems of differing expectations of the service. Some people may be unhappy with the number and range of needs of some residents, some of whom may have a range of issues such as levels of dementia and forgetfulness, mental health needs, learning disabilities and mobility issues".

The care manager at St Bartholomew's Court responded to this by stating: "We have no dealings with leaseholders before they arrive into the building as this is dealt with by our sales team. Otherwise they would have been informed that care was provided here. This is something we have picked up on with the sales team and clients are now told."

In some services there was some confusion about what they were paying for. This was particularly so for those people who had purchased their flats. Having said this, the care managers spoken with were aware of some of these matters and dealing with them. In some services, a few people who had been at the extra care service for many years, moved in under an old contract which had been replaced by a more current one. What people paid for had changed.



This matter was often related to payment for the food provided. Lunch is provided in all services. Generally, for those people who had purchased their flats, they did not have to pay for the food, i.e. they could opt out. However, for those people who are funded, the food is part of the contract of residence and so they have no choice but to pay for the food, even though they may not have the lunches. During this review people spoke about the main meal (food) that was provided was lunch.

Accommodation

All the extra care services are purpose-built premises and so relatively new. We concluded that the premises for all extra care services are well maintained, clean and bright. Corridors are generally wide and accessible for people who use a wheelchair. Flats were seen as of a good standard, all being self-contained. People spoken with were happy with their flats and the space they had.

In a minority of cases, some issues were identified about the building. Some issues were identified at Downlands Court. A number of people said there had been problems with the heating. One person said the windows were "draughty".

Some people, particularly at Downlands Court in Peacehaven, St Bartholomew's Court in Rye and Margaret House in Uckfield, said transport was a problem. The key issue is that all three are not near to local amenities. Ways of overcoming this have been attempted by the services. For example, the manager at St Bartholomew's Court stated: "We do however have a local bus to go to the local supermarket, a dial a ride bus can be booked by the client and taxis operate within the area." Good use is made of volunteers to assist with transport, particularly at Newington Court, Ticehurst.

The best thing about living in extra care

All people spoken with were able to come up with something that was good about the extra care facility they lived in. The main themes were that people appreciated that they had their independence and own front door. It was their home and they controlled who they let in. They also liked the idea of having carers around at all times should they need assistance in an emergency. Safe and secure were the key words used regularly.

People also told us that they enjoy the company and living with others, whilst keeping their independence. For example, one person at Cranbrook said, as their best thing, "coming down and talking with other residents". In most services, there was a sense of community and shared living. The exception was some issues at St Bartholomew's Court. The report for this service concludes "Overall, Authorised Representatives concluded that, for many residents, there was a sense of isolation and unhappiness. There was little sense of it being a community of people." The managers were very aware of this issue and working hard to resolve it. There had recently been a reorganisation within the provider organisation, and this may have been a factor. There were also differences between the views of those who need care and support and those who do not i.e. those receiving



personal care at St Bartholomew's were more positive about the quality of the care and the running of the care home compared to those who did not receive any personal care This is not helped by the larger than average number of people who do not require any care.

When asked 'what is the best thing about living in extra care?' people gave us the following responses:

- "It's everything you could wish for" (Newington Court)
- "Nice and quiet and peaceful" (Newington Court)
- "It's warm and help is always around" (Newington Court)
- "Home from home and top notch" (Marlborough House)
- "Care is at hand and living independently" (Marlborough House)
- "Just being here and having my own place. I'm so happy and pleased" (Marlborough House)
- "Independent living" (Margaret House)
- "Flat is lovely" (Margaret House)
- "Wouldn't want to live anywhere else 10 years' happiness since I have been here" (Margaret House)
- "Own flat and freedom to come and go" and "enjoy independent living with care" (Cranbrook)
- "Maintaining independence" (Cranbrook)
- "Feeling safe, someone to care for you" (St Bartholomew's Court)
- "My own flat good social events" (St Bartholomew's Court)
- "Care and company" (Bentley Grange)
- "I fell in love with it straight away" (Bentley Grange)
- "Being looked after" and "not lonely and alone" (Bentley Grange)
- "The company and so I'm not alone" (Downlands Court)
- "Feel very safe" (Downlands Court)
- "People to give a hand, when needed" (Downlands Court)
- "I like people around me, not alone. I go into the dining room and sit next to someone. Sometimes we don't say a lot but it's just the feeling of being in someone's company" (The Orangery)
- "Peace of mind, I got no worries" (The Orangery)



What could improve

There were no issues around improvement that were common to all services. The only issue raised in a couple of services concerning the provision of care was that some people thought there should be two carers at night. However, no one could give an occasion when they were aware that two had been needed.

One theme that arose in a few services concerned the food. Many people at Bentley Grange and The Orangery said the quality of the food could improve. There was also some confusion about payment for the food in some services. People explained that they had to pay for their food whether they wanted it or not, as it was part of their contract.

Another issue for some was the building being quite isolated. As a result, transport to local facilities and sources could be an issue for some. At Newington Court, Ticehurst, volunteers and volunteer services were used to assist people with transport.

Some people came up with quite individual and specific ideas. One person suggested an exercise room and another a bar so he could have a pint!



3. Discharge from hospital

All seven extra care services returned the questionnaire about hospital discharges. They reported that 60 people had been discharged from hospital back to their services in the last six months. Care managers reported that of these, 14 returned without the hospital informing the service of this. In the main, the hospital arranged any follow up services, but this was not consistently the case. Some care managers reported occasions when district nurses are not informed by the hospital that someone has returned and so they have to do this. Care managers reported that they always follow up with the necessary services when a person returns to them from hospital to make sure they are aware that the person has returned home.

A couple of care managers gave examples of poor discharges from hospital. One person was returned home, and the care manager was not informed. The care manager stated: "the client had to be readmitted the same day as was not well enough to be home. The hospital did act swiftly and take the client back to hospital within a few hours".

Another care manager reported: "I did not want to take someone back who could not feed himself and was obviously not fit for discharge. I was told I had no choice but to take him back that day. He got home and could not feed himself, could not mobilise and could hardly talk. I had him sent back in that same evening."

Another person was returned to the extra care service even though she had no care package and needed blood sugar levels checking at least every 40 minutes. Despite this, the hospital sent the person back home, even though they were told this was unsafe. She had to be returned to hospital that day by ambulance after she was unconscious for about 40 minutes.

Overall, care managers thought discharge from hospital worked well and had good relationships with other healthcare professionals such as GPs and district nurses. Sometimes there can be communication issues between the GP surgery and pharmacy, which can result in late delivery of medication.

The key issue raised by care managers was that hospitals, and some healthcare professionals, do not understand what extra care services are. They believe they see them as care homes, which they clearly are not. One care manager stated, "health teams" (these can be multi agency teams), do not understand what extra care is, they think it's a care home". Another care manager reported "most wards seem to think we are a care home and therefore think that we are able to do more than we can. Many wards also think that there will be someone available to receive someone back from hospital any time of the day or night. This is not always the case particularly at weekends".



Care managers were asked to rate the discharge from hospital in the last six months with a score from 1, being negative, to 10, being very good. The scores ranged from 3 to 8. The average score for all seven services was 4.5.



4. Action points - to inform discussions with providers and commissioners

- a) Extra care services could assist in setting up residents' committees where these are not in place. This will assist in the development of activities and events as well as provide a forum for feedback direct to the care and accommodation providers.
- b) Adult Social Care could review their contract with extra care services to ensure that some aspect of the funding includes the provision of activities, to assist in developing these.
- c) Extra care services need to ensure that people who purchase their flats are provided with a full explanation of the nature of the extra care service and level of care and support some people may require.
- d) Some of the anomalies between those people who have purchased their flats and those with a tenancy, such as the payment of food, could be reviewed.
- e) Ways of assisting people with transport to local services could be explored, such as linking with volunteers and volunteer organisations.
- f) Hospitals need to advise those staff who are involved in the discharge from hospital about what extra care services are, stressing that they are not care homes and need to be seen as people returning to their own homes.

The following comment reflects a common theme echoed by people living in Extra Care accommodation:

"I feel very safe"



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Disclaimer

This report relates to findings observed on the specific dates set out in the report. Our report is not a representative portrayal of the experiences of all service users and staff, only an account of what was observed and contributed at the time.

A final version of this report will be publicly available by mid September 2019 via our website and circulating it to Healthwatch England, CQC, NHS England, Clinical Commissioning Group/s, Overview and Scrutiny Committee/s, and our local authority.

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Appendix 1 - Healthwatch East Sussex enter and view programme for extra care facilities: prompt sheet/ questionnaire for residents/tenants

Name of extra care service:

1. How long have you lived here?	
2. Were you offered a choice of care organisation, such as a previous one, or did you have the one in-house?	
3. Do you get support and help when you want it and for long enough, including at night?	
4. How many different carers do you see each week?	
5. Do you get on with all carers?	
6. Do carers arrive at the agreed time or are they sometimes later than expected?	
7. If you need more care and support than usual, is this allowed and is it arranged?	
8. Are you involved in agreeing your care plan?	
9. Do have good access to healthcare services or are there any gaps or barriers?	
10. Who else comes to visit you and do you go out much? What about activities in house?	
11 What's the best thing about living here?	
12. What could be improved and what do you wish for?	



Appendix 2 - Healthwatch East Sussex enter and view programme for extra care facilities: questionnaire for care managers

Name of extra care service:

Date:

1. How many people have returned to the extra care service from hospital in the last six months?	
2. How many of the above discharges from hospital were you informed of in advance?	
3. Did the hospital, as part of their discharge duties, arrange any necessary follow up from healthcare professionals such as OT, Physio, SALT, district nurses?	
4. On a scale of 1-10, with 1 being negative and 10 very good, how would you rate the discharge from hospital in the last 6 months.	
5. Any other comments about discharge from hospital.	
6. Do you consider the residents at the extra care receive a good response and service from other healthcare professionals and services when residents need them.	
7. Any other comments about your work with other healthcare providers	
8. Any other comments about the extra care service that you think would assist us in understanding your extra care service.	



Appendix 3 Healthwatch East Sussex enter and view programme for extra care facilities: prompt sheet/questionnaire for tenants not receiving personal care

Name of extra care service:

Date:

 How long have you lived here and why here? 	
2. Do you have to pay a retainer or other fee to have access to the care and support workers based at the extra care? How does that work?	
3. If you did need some help from carers, will you have to use the in-house ones or could you go anywhere?	
4. Do you have good access to health and social care services such as GP, day centres etc? Are there any gaps or barriers?	
5. If you need help to access services, eg making appointments and transport, where do you get this from?	
6. Have you ever had to call for assistance from the carers based in the extra care service? Do you have a call bell?	
7. Are there events and activities organised at the extra care and if so, do you get involved?	
8. Can you influence what happens here such as through a tenants/residents' group?	
9. Are people able to visit you when they want or are there any limits?	
10. What's the best thing about living here?	
11. What could be improved and what do you wish for?	