



**Midlothian**  
**Health & Social Care**

# **Patient Feedback**

## **Community Respiratory Team**

2019-2021



The Midlothian Health and Social Care Partnership is responsible for services that help people live well and get support when they need it. This includes all community health and social care services for adults in Midlothian and some acute hospital-based services.

As part of continuing to improve our services we collect feedback from people who use our services and their friends and families.

We collected informal feedback from patients through comments, cards and formal questionnaires between 2019 and 2021. We would like to thank over **100 people** (and 26 staff) who took time to share their views.

# Key Points

The feedback from people who use our service, their friends and family and the other professionals who support them has been overwhelmingly positive. People mentioned many areas that they found helpful including:

- **Information**
  - People spoke of the fact that they felt they had an improved understanding of their condition, and this greater confidence helped them feel they had meaningful choice and control over their treatment. The team are all trained in 'Good Conversations' and many people spoke of having confidence in the skilled, trusted staff who can explain things that are relevant to their lives.
- **Holistic support,**
  - People mentioned how approachable and friendly the team were and how they felt comfortable with them. People didn't feel they had to repeat their story and felt the team kept them 'safe' – with proactive monitoring and work on prevention such as encouraging physical activity and a healthy diet. Family members often mentioned how they felt supported – which in turn allowed them to support the person they cared for.
- **Access to other services**
  - People spoke of the support the team gave them in accessing other services – such as organising medication, providing equipment, referring them to secondary care or third sector services. They spoke of fast, rapid support when they needed it.
- **Future Planning and Palliative Care (including supporting people to access Marie Curie and end of life services)**
- **Support in a Crisis**
  - Many people spoke of the role the team played in preventing a hospital admission - for a number of reasons. These included being able to be seen by the team directly, having access to other services and using techniques to prevent them going into hospital such as coping with anxiety.

# Information

A number of people commented on the benefit from being able to access information about their condition from skilled professionals.

## Key Points

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Some people commented on a **support to understand their condition**



"We really feel the benefit of your input. No one has ever tied everything together and explained it like you do. We feel like we understand everything so much more now and we are able to make better choices and we feel more confident and comfortable doing it."

"It's been really helpful to have someone sit down and take the time to explain more about COPD."

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Some people commented on having **more choice and control**.



"Thank you so much for explaining DNACPR to me. You have taught me so much in a short space of time. I really understand it now and will think about what I want to do."

"You really listen to what I want and it's not just about telling me what I should do. I have a lot of trust in you and your team, you have helped me so much."

"Thanks passed on... for helping explain about in flight oxygen systems / fitness to fly etc."

"\*\*\* (Psychologist) has really helped me understand what is going on. I find her help really useful"

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Some people commented on the **ease of accessing information**.



"Complimented the team on how accessible the service is. It means a lot to be able to call a number and know you will get an answer from the right people. Easy to access and always helpful advice given."

# Holistic Support/Prevention

People commented that the support they received helped them in all areas of their life

## Key Points

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Some people commented on how the service has supported them to be more **physically active**.

“\*\*\* (Psychologist) has really helped me understand how to manage. He has been my saviour and I now feel able to go some gym classes on my own.”



“\*\*\* (Psychologist) work has been fantastic. Before seeing \*\*\*, I had been referred to MAC by my physiotherapist to help me attend a swimming class, as this is something I enjoyed doing previously. However thanks to \*\*\* input, I have been able to go swimming by myself and no longer need to use MAC as he has helped me to build up my self-confidence and coping strategies. \*\*\* has been my saviour in helping me understand and deal with my anxieties associated with my COPD.”

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Some people commented that the service has supported them to **stop smoking**.



“I stopped smoking because of your team, you referred me 2 years ago and I stopped then and I am still not smoking, so thank you”

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Some people commented that the service supported them with **their diet**.



“The dietician has been great, I can’t believe what I can eat now and the weight is starting to go on.”

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Some people commented that the service supported them to **feel connected to others**



“Patient who had been shielding...., too anxious to go to shops..... Set goal to go out daily and pick up 1 thing from local shop. Put into place advice and has managed to go for a daily walk and go to shops.... She is absolutely delighted as is her partner who didn’t know how best to support her. She expressed her gratitude for the service knowing she can call on us at her next exacerbation but also for the more in-depth work carried out to enable her to go out again. She is using her MDI (change to inhaler device) with a new aerochamber to effectively manage her SOBOE (Short of Breath on Exertion) when going out and feels confident to go for a walk now that she has some better symptom control too.”

“Thanks to you I have a buddy system now from the Marie Curie centre. We go out every Monday for lunch, shopping or something nice and we get on really well. I can’t thank the team enough for what they have done for me.”

## Key Points

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Many people mentioned the benefit of knowing someone was **proactively monitoring** them

“\*\*\* and wife and extended family all pass on their huge thanks to the telephone support during their COVID symptoms. Great comfort to patient, his wife and their extended families that we were involved and monitoring by the phone.”

“\*\* said she would be lost without us, very grateful for all the shielding advice and reassurance”

“I would be lost without your input”

“thank you for your care and attention it has definitely helped me manage my condition better”

‘Couldn’t do it without you all’ regarding management of her COPD symptoms at home.

“thank you for all you do for my mum, I know you are busy but you don’t forget about her”

“Delighted at input and check-ups – feeling very well supported.”

“Incredibly grateful for all the work we have done for \*\*\*, so grateful for all the regular communication and keeping her in the loop. \*\* feel so much more confident in managing \*\*\* now that we are involved.”

“Compliments for whole team , has never been looked after so well by anyone”

“Really value your input you have just been so great and I have been feeling so unwell. You’ve supported me at home so much”

“thank you so much for supporting and organising care”

“can’t praise team enough, MCRT are her own personal “ Charlie’s angels “ so much trust in MCRT”

“It really helped her mum to know we were on the end of the phone.”



## Access to other services

People mentioned being linked to other services. Primary Care Professionals mentioned how beneficial they found the service.

### Key Points

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People commented on the support from the **Physiotherapists/Post Exacerbation Rehab Therapy**

“Very grateful for the physio input”

“Thinks the girls (physio team) are amazing, They are angels. He is so grateful for their input, for all of our input and he feels very lucky to be able to receive this in his home and improve his quality of life.”

“You referred me to Pulmonary Rehab (PR) which I cannot recommend highly enough. Everyone should have the opportunity to go to PR and I am grateful that you organised it. Your help in understanding what to do has been brilliant and I wouldn’t hesitate to call you.”

“big thank you for Post Exacerbation Rehab Therapy input and for what all the team do”



## Key Points

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Many professionals mentioned that **Primary Care staff appreciated the support of the Team.**

"GP - Grateful for the service we provide. Great to have professional to professional discussions. Feedback that more bodies on the ground are required."

"GP – massive help in managing our complex respiratory patients particularly at end of life care" thanked us for our input and coordinating care for these really difficult patients."

"GP - Thanks to you and the rest of the CRT for all your good work"

"GP - extremely thankful for all we have done and are doing for a patient in their practice."

"GP - thanked for involvement in a difficult patient management – we were able to sort out a pathway for her to improve her clinical care and he was grateful for input."

"GP - commented that the teams involvement with \*\* (a patient) has been so beneficial and a huge saving of work for the GP team at the practice."

"Nurse at \*\*\*\* (Nursing Home) we feel better able to manage them with LTOT with your support."

"care home staff from \*\*\* (Care Home) thanked team for all the involvement regarding \*\* (Patient) oxygen wean"

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People commented on the support with **medications**

"Thanked us for advocating for her with GP and pharmacy. Feels this has helped her mental and physical health."

"Very grateful for the swift response in sorting out her inhaler issue. You are lovely, easy to talk to you. Thanks so much for sorting it out. I was really pleased it was done so quickly."

"Thank you ....for organising new inhaler so quickly"

"Very happy that you managed to get all my medication delivered to me so quickly when I was running out. Also happy that our treatment has kept him out of hospital and he feels sure if he hadn't had treatment at home he would have admitted"

"thank you, I would not get my prescription without you"

"Very grateful for all support received to help him get neb and ambulatory oxygen appt."

"thank you for the care, much appreciated (organising nebulas to ease extreme Shortness of Breath)"

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Some people commented on the benefit of **equipment**

"\*\*\* was incredibly helpful and his suggestions for equipment are going to make such a difference to me I was brought to tears."

"family thanks us for input – happy with getting equipment in place to palliate"

"thinks we are wonderful as we got all the equipment very quickly. Really delighted."

# Anticipatory Care Planning & Palliative Care

A number of people commented on the support they received at end of life.

## Key Points

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Many people commented on the **high quality of the support** they received

“Husband stated that the care his wife received towards the end before she died was second to none and he was very grateful for the support.”



“GP emailed following death of a patient we were involved with thanking us for our input to enable the patient to remain at home where she wished to be”

“we would just like to thank you for the love, care and support you gave to \*\*\* before he passed away”

“Daughter phoned to thank her for all the involvement in helping her mum in a palliative situation.”

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A number of people commented on the support they received with **planning for the future.**



“complimented on anticipatory care planning and care of her husband who passed away”

“Daughter expressed that the recent consultations had around ACP and expectations of care with MCRT had really helped the family and the patient understand her symptoms and possible avenues of support.”

“Really appreciate you explaining ACP to me, no one has ever explained it to me like that before. Now I understand the process.”

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Some people commented on how the team **links with other services**



“\*\*\* (Marie Curie nurse) – thanks us all for input thinks it is valuable for end stage patients with COPD and linking the service with Marie Curie hospice services.”

“\*\*\*\*\* (GP practice) found our input into the palliative care meeting very helpful”

# Support in a Crisis

## Key Points

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Many people commented that being able to **be seen by the team directly prevented a hospital admission.**

"would have admitted on sat if hadn't been seen by the team"

"Feel a lot more confident in managing breathlessness and getting fast treatment"

"thanked for video conferencing very helpful and all the efforts preventing her hospital admissions"



"Dr \*\*\* at Loanhead Medical Centre ...let me know ... that she had found our team particularly helpful in managing some of their COPD patients and keeping them out of hospital."

"Your team are definitely reducing his A&E admissions. The Respiratory Nurse Specialists team used to repeatedly get called to A&E now we are not seeing him as often at all."

"Felt he was deteriorating with his breathing and the support and medication management kept him out of hospital."

"Scottish Ambulance Service call responded patient and daughter felt much more comfortable having had call from us."

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Many people commented on how they use **techniques the team have passed on and how this reduces calls to hospital**

"I have learned how to deal with panics, I no longer phone the ambulance straight away, I take my nebuliser first and try to do my breathing exercises"

"because of the help I have got at home now, I feel like I am not going into hospital as much"

"I don't know what I would have done without your service, it has helped me stay out of hospital and manage my chest better"

"if I didn't have your support and the use of the nebuliser at home I would have called the ambulance"

"Was frequent attender at A+E and often called Scottish Ambulance Service. Engaged well and understood his responses in relation to past events. Worked together to find accessible and acceptable strategies for avoiding these – has been using well and has reduced call outs and attendance due to using strategies except when appropriate."



"This team has really worked for me, I get the time that I need with the nurses and \*\*\* spends time with me twice a week."

"Would have had many more hospital admissions if the team wasn't involved."

"Settled down after 5 mins and was fine, before would have called ambulance. Now knows to try this first."

"Thanked us for helping to stabilise symptoms. She is delighted with progress and feels that symptoms are well controlled and she is confident to keep going and she will call us if required. She has avoided multiple hospital admissions."

"Complimented the way she is managed, keeps her out of hospital and she knows exactly what she is to do and that gives her confidence."

"The team are fantastic, amazing. I'm so glad they have helped me stay out of hospital so that I can look after my wife."

"You have been a god send. Using the nebuliser during my infection gave me such relief. I am so pleased I can call you."



## Key Points

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### Many people mentioned the importance of **reducing anxiety in managing their condition**

"thinks the service is great, was telling the nurses in the hospital and the GP that it is very reassuring to have the help and care that was not there before, and that normally she panics if her breathing is bad, but now she feels much more settled knowing that there is a team she can call and have support visits from. She is also benefitting from \*\*\* the psychologist input in managing her feelings of anxiety in a more controlled way".

"great service, can't thank you enough for the care and attention, you have definitely reassured me in the management of my breathing problem"

"I think your service is great. Without it I would be in hospital so many more times over the last year. I feel so much more confident and the team really understand my problems"

"Was suffering with extreme anxiety and panic and would not leave house or attend for any health appointments. \*\*\* worked hard on understanding the cause of his anxiety and panic and used the techniques well. He has since reported attending for appointments and has been out on his own to do shopping and visiting Galashiels on public transport. Is now engaging well with Poppy welfare Scotland"

"Thank you so much, I could not have done it without you." Is working on reducing anti-anxiety and opioid medication.

"Was struggling with anxiety, particularly when using the toilet. Engaged well and had good positive family support. ... Is now able to use the toilet freely and has reduced his opioid medication as a result.

"Was too anxious to leave house. Did work on anxiety cycle and used strategies associated with this. Has now being going out regularly with family and has attended Fatigue and Breathlessness class at the Marie Curie hospice."

"Suffered with several panic attacks daily, very anxious to leave house. Has attended FAB and was sitting waiting at dining table instead of lounge chair on last visit. Understood her panic in relation to past events and reported that her panic attacks have reduced greatly since intervention and has reduced use of medication."

"couldn't praise the service that provide enough, he said its amazing and kept him out of hospital and that's so important now that wife is so poorly. "your bread and butter is my lifeline"



### One person asked if the **service could be expanded**.

"Why can your service not be available at the weekend, it would definitely help me avoid hospital as I mostly end up going in at the weekend."



### Some people commented on support if they **were admitted to hospital**.

On discharge from admission with COVID positive result "wanted to thank us for supporting her on the decision making around admission to hospital and all we did for her."

"Patient complemented saying had found the teams input super helpful and don't know what he would have done without it following hospital admission where he was seriously ill"