

Walsall Together: Respiratory Care Pathway

Patient Engagement Report

1. Introduction

Walsall Together is an integrated care partnership between the organisations that plan and deliver health, mental health, and social care services locally. They include:

- Walsall Healthcare Trust
- Walsall Clinical Commissioning Group (including local GPs & Primary Care Networks)
- Black Country Healthcare NHS Foundation Trust
- Walsall Council
- Walsall Housing Group
- One Walsall

One of the key aims is to help the population of Walsall stay well for longer, by supporting them to make better lifestyle choices to help them to live independent, active, and healthy lives. It is about helping people stay out of hospital when possible by providing accessible, co-ordinated, and responsive care as close to home as possible. The aims of the partnership are to:

- Improve the health and wellbeing outcomes of their population.
- Increase the quality of care provided; and
- Provide long term financial sustainability for the system.

Healthwatch Walsall (is an independent champion for people who use health and social care services whose role includes finding out what matters to people and help make sure their views shape the support they need) have been commissioned by Walsall Together to capture the patient and service user voice around care pathways and living and managing with long-term health condition(s). The focus has been on the 6 priority Key Line of Enquiry around Diabetes, Respiratory, Cardiology, Mental Health, End of Life & Palliative Care and the best start in life, early child. This report concerns the outcome of engagement work undertaken in relation to respiratory disease.

2. Respiratory Illness in Walsall

115,000 people a year die from lung disease in the UK, equivalent to 1 person every 5 minutes, and every day, 1500 people are newly diagnosed with lung disease. Moreover, the health outcomes for people with lung disease have not improved over the last 10 years to the same extent as other diseases such as cardiovascular disease and cancer. The mortality rate (the number of people per 100,000 dying) of people aged under 75 from respiratory disease in Walsall is 48.1, which is significantly worse than the national rate of 34.2.

There were 5040 emergency hospital admissions for respiratory disease in 2018/19 in Walsall. Hospital admissions due to respiratory conditions are a major factor in the winter pressures faced by the NHS and lung disease costs the UK more than £11 billion per year including the impact on the NHS (£9.9bn), and wider economy through working days lost (£1.2bn).

Chronic obstructive pulmonary disease (COPD) is the name given to a range of lung conditions which can cause breathing difficulties. In addition to lung cancer and pneumonia, COPD is one of the 3 leading respiratory causes of death in England and is the fifth biggest killer overall in the UK, accounting for 5% of all deaths each year.

In Walsall, about 2.5% of the population have COPD, which is worse than the national average of 1.9%. In Walsall, the mortality rate of COPD is 64.7, compared to the national rate of 51.7.

Around 86% of these deaths are caused by smoking, and hence are preventable. Given the high proportion of these deaths that are due to smoking, a reduction in the prevalence of smoking would reduce the incidence of COPD and extend the life of those with this illness, as well as prevent or shorten hospital stays and reduce days lost from work.

Around 19,660 people in Walsall have asthma. In 2018/19 there were 260 emergency hospital admissions in adults and 185 admissions in children for asthma. The mortality rate from asthma in Walsall is 3.95, compared to a national rate of 2.36.

Avoidable mortality due to respiratory disease is 7 times higher in the most socioeconomically deprived areas in England, and therefore, respiratory disease is a major contributor to the overall life expectancy gap between the rich and the poor; and the gap is widening. This inequality is related to a multitude of factors, such as greater exposure to risk factors (such as smoking, air pollution, poor housing, and occupational hazards) as well as variation in healthcare quality and access. In addition, there are specific groups that are at significantly higher risk of respiratory illness, such as people with severe mental illness, people with learning disabilities, and the homeless.¹

What the above analysis helps to illustrate is the impact respiratory disease has on the population and the importance of having a care pathway that responds to patients and carer needs at all points of the disease progression i.e., in primary care through to emergency care and hospital admission and access to specialist services.

We believe the Walsall Together respiratory pathway has as one of its central aims to support patients in the community for as long as possible with access to acute and specialist care when the need arises. We understand that care will be provided by trained professionals in suitable environments across the care pathway and that some patients will be self-managing their condition

¹ References:

Inhale - INteractive Health Atlas of Lung conditions in England – Public Health England. <https://fingertips.phe.org.uk/profile/inhale>
All Our Health: Respiratory Disease – Department for Health and Social Care. <https://www.gov.uk/government/publications/respiratory-disease-applying-all-our-health/respiratory-disease-applying-all-our-health>

and know how to manage exacerbations. However, this project is testing how effective the pathway is, in meeting patient needs and to identify things that are working well and those that are not where improvements could be made that benefit both providers of respiratory care and those receiving it working together i.e., meeting the Walsall Together principle of co-production.

3. Methodology

This report is the culmination of engagement work undertaken and co-ordinated by Paul Higgitt, Senior Engagement Lead, Walsall Healthwatch, and Phil Griffin, Walsall Together Service User Group Chair. It is based upon a number of individual patient stories and 2 respiratory workshops attended by 36 patients and service users around living and managing with respiratory conditions held during November 2020. We have structured the report so that it summarises key findings and recommendations early on and included as Appendices to the report, the notes of the virtual workshops held in November 2020 and individual patient stories.

4. Respiratory care pathway: summary of recommendations

From the engagement work undertaken through the project the recommendations for improvement applicable to the Walsall Together Tiered Model of Care are as follows:

Tier 0 – Resilient Communities

- I. Opportunities for patients to share experiences and advice through a variety of virtual and ultimately face to face opportunities to help each other and also to seek advice from respiratory care providers.

Tier 1 & 2 – Primary Care & Community and specialist services

- I. Better medication optimisation, advice and support and timely medication reviews as part of a shared decision-making process
- II. Ensure that there is consistency of respiratory care across General Practice during this challenging period that patients are accessing their reviews.
- III. Better communication with the patient through Acute, Community and Primary Care
- IV. Enhanced advice around the importance of pulmonary rehabilitation and increase uptake and reduction in those who do not reattend after finding sessions challenging.
- V. Improving Access to Psychological Therapies-More information and promotion of the IAPT / Talking Therapies service for people with respiratory conditions.

Tier 3 – Unplanned Care

- I. Whilst there is considerable work undertaken to keep patients out of hospital at crisis point, there are circumstances where it is necessary for patients to attend for unplanned care. More access to contacts for advice particularly out of hours for patients who do not have access to the community respiratory team, out of hours support.

Tier 4 – Acute Care

Through our engagement we did not receive any recommendations on improvements around this tier.

5. Patient engagement work undertaken, on which the report's findings are based.

Respiratory conditions can be very distressing for patients. The workshops and the experiences of patients and their carers who participated just emphasised the impact that having a respiratory condition has on everyday living and why access to the right support, with the right information at the right time in a timely way is so important. It was also clear from what people said that crisis intervention as well as ongoing support to help patients manage their condition is also very important. All this serves to highlight that the local respiratory care pathway needs to work well so patients can remain in the community and avoid unnecessary exacerbations of their respiratory condition which eventually could require an urgent GP domiciliary visit or a visit to A&E and even admission.

The workshops captured a range of intelligence and that the comments on what could be improved and what could be done differently would be of interest to commissioners and could be used to support improvements in the care pathway in the spirit of co-production.

We also have some data gathered through the individual 1:1 patient stories which we have used to strengthen the report.

6. Some of the key things patients and carers shared.

- I. It is key that patients worry about the future, living with the disease and that this impacts on the patients and family members greatly.
- II. Patients / Service Users have found talking to others about their conditions through such means as these workshops has been positive. It has given people the opportunity to share experiences and give each other advice and support in managing their conditions. Some participants highlighted that they would like to see a Respiratory Support Group established for people to share experiences and get advice from professionals.
- III. It is evident that the support from the community respiratory team is very positive and great efforts are made to support patients to help avoid crisis point exacerbations. However, some patients are not known to the service for a number of reasons and would rely on accessing other support through their general practice / 111. 2 patients informed us that at times of exacerbations that they have called 111 and had been admitted into hospital, and where there may have been admission avoidance if they could have accessed community support.
- IV. More information and telephone numbers for advice and support with managing with a respiratory condition not just GP access. Provide opportunities for patients and carers access hints and tips of self-management. One patient in early stages of COPD seemed to be kept in the dark until access to Community Teams.
- V. It is however about striking a balance between demand and capacity within the system.
- VI. Patients also informed us that there was confusion around some of the treatments and there was advice given from a patient to a patient within the workshops about accessing additional equipment. Medication optimisation is key but that this also needs to be a shared decision

process with medication reviews.

- VII. There have been useful discussions that some patients said that are self-taught in managing their condition and that they would like more training and to be more informed. Would have liked more knowledge to question and challenge and know more details. However, some people do not want to know much about self-management but are heavily reliant on service providers. Reviewing patient knowledge of medication is important and that the patient needs intervals of medication reviews as their conditions may change.
- VIII. The support offered through the respiratory rehabilitation teams in the hospital and at Heartcare were generally positive however several patients informed us that they were worried about strenuous rehabilitation as they were worried that this having a detrimental effect on their condition, which meant that several patients decided not to reattend rehabilitation.
- IX. There were also several conversations about triggers in their conditions and how to manage these triggers were possible. However, pre and during COVID-19 some felt that they were either unable to access their GP for advice or support / investigations through GP care were limited.
- X. The psychological impact of breathlessness has been identified as a significant concern for many patients, and also the constant worry about time, when will the condition get worse, how long do I have left etc. We were informed by some participants.
- XI. The linkage between accessing timely mental health support is important. Through the discussion we had conversations around coping mechanism and support. We highlighted that for some accessing services such as IAPT support people through the IAPT and long-term health condition programme, however very few of the participants had knowledge about this service.
- XII. Not all patients / service users had smoked tobacco through their lifetime but were impacted as a result of heavy industry and pollution. We were informed that there is for some a stigma with having a respiratory condition as some view the cause of being related to personal unhealthy activity.
- XIII. The impact on respiratory conditions for patients with other long term health condition is clearly evident. Managing other health conditions such as diabetes and cardiac conditions at the same time is vital. For some participants told us that symptom management can be difficult in understanding that is making the feel ill.



7. Conclusion

Walsall Healthwatch, patients, and members of the Walsall Together Service User Group want to see Walsall Together commissioners and providers of health and social care, to act in a demonstratable way to the intelligence provided via this report and in particular the specific recommendations given earlier.

It is only by tangible and measurable improvements made, can it be said that the principle of co-production of care pathways is being achieved in Walsall and that the words in the Walsall Together terms of reference which are based on strong partnerships and working together with service users are not just rhetoric.

We recognise that during this challenging period commissioners and providers of services have prioritised efforts to support those affected by the COVID-19 pandemic and that some developmental work around co-production will be challenging. However, there will be some improvements that can be made relatively easily while others will take longer and will need clinician time and leadership.

Paul Higgitt – Senior Engagement Lead, Healthwatch Walsall
Phil Griffin – Chairman Walsall Together Service User Group



Appendices

Appendix One - Key Points from Respiratory Workshops

Appendix Two – Patient Stories

Appendix One

1. Key Points from Respiratory Workshops

- Hints and tips for living and managing with a respiratory condition and improving quality of life are really important and sharing information on medication and equipment.
- British Lung Foundation provide a good range of quality materials and advice to support service users.

2. Do you understand your condition and how it impacts on your health?

Based on personal views:

- Dad knows he has what he calls a breathing condition COPD but due to his age does not know exactly what it means. Daughter did not know what it meant until she went to the GP to find out what it involved. Uses Google to find out it was bronchiectasis and that it was irreversible. Know what is causing this and getting worse. He is also aware it is not going to get better. As this impact on his life, my dad is not able to do what he wanted to do. Having to use a wheelchair and he gets very upset.
- Diagnosed with a rare condition amphiphilic asthma not diagnosed until 39 on top of COPD. Not all patients know that COPD is an umbrella term. Struggle with stairs, walking and limited mobility.
- Some of the service users highlighted that they had wider concerns about the dangers of COVID-19. We were informed that some patients were absolutely petrified due to COVID.
- Treatment under Walsall Dr Matton Hudsey, 3 years ago trial drug – MEPO and results were amazing. Was attending hospital about 10 times year with severe respiratory distress but have not been in hospital for nearly 1 year. Problem it is a progressive disease and at my age cannot do the usual life things. Stopped maintaining family relationship because of the risk. However respiratory nurse from Walsall has still been calling me to check up.
- Other service user has COPD, but the consultant indicated that it was not oxygen levels but breathing and getting progressively worse can now do very little. Accessed pulmonary rehabilitation but found it a bit too much. However, pushing more helps lungs but had a bad experience and it put me off. It is about maintaining the sessions and found a difference but now it seems to be getting worse with no sessions due to COVID. You have to do pulmonary rehabilitation at the hospital for a good couple weeks to see benefit.
- I take Hypertonic Saline in the morning before doing anything found rather than liquid use hypertonic and keeps lungs open more. Other service users in the workshop did not know

about this. It has also helped spirometry on testing capacity.

- Confusing for some, some use nebulisers, and others trimbo and blue inhaler.
- Spiro understanding is really important as it gives a good indication of where we are at in terms of the disease. One at home tube but hospital spirometry different as it records more information.
- Husband recently diagnosed with IPF and do not know how long he has left but due to COVID telephone conversation is all we have had. Under Walsall GP. His journey – knowledge of condition is very limited. No one has sat down and explained the condition, other than in next 6 week will be on a trial medication. Asked what prognosis is and told will discuss this when you come in. Referred to QE from GP. 12 weeks coughing he was not happy to be fobbed off. After CT scan but then all was closed down to us due to COVID and Biopsy in QE and results in December 2020.
- Have Bronchiectasis diagnosed 2004? Thought it was asthma. Saw consultant at Walsall Manor and had a scan. I continue medication until last 2 years my condition has deteriorated and now having 4 to 5 episodes year. Rescue packs work most times but In May it was not working thus changed antibiotic. It's a hidden disability. When there was no traffic and warm it was great. Last October 2020 had COVID and it put me on my back for the best part of 2 weeks. Still struggling to get about in November but the rescue pack has helped with the Prednisone.
- Breathless all time, having to sell our house due to the increasing difficulty with the stairs. People do not recognise it as a disability. It does not just physically affect but mentally and now on tablets due to mental health. I also have diabetes and find it very difficult to manage this at the same time. Husband Bronchiectasis and COPD and deteriorating over time. It affects me as his carer physically and mentally.
- Been back and forward with my GP, medication changes regular, and now on Relvar because I approached GP and had reviews, was still having flair ups. As things moved on moved from Serio Type 250 now onto Revefenacin. Have fibrosis in bottom of lungs and as scarring increases. Realised it must be managed and that will never be cured.
- Its more understanding from others, do class it as a disability. I understand my treatment and condition but not all do. When sat down with right people they have helped. My employer also keeps an eye on me which is positive.

3.What Could be Improved?

- An integrated approach such as at Heartlands is much better for the patient.
- Admitted into AMU at Walsall Manor in November, treatment well explained, however mother-in-law has COPD and was admitted. She is over 80, she was moved around a lot and

the main issue was communication when called told she was moved and chasing around a lot. She was told if you improved you will be coming out tomorrow, but she heard she was coming out and this was confusing. It is about the definitive communication.

4. Positives in Care Pathways

- Went to GP, choice to go to QE as they had more detailed records and select choice. Now at self-management stage with NEPO. Requested review. Self-administration of rescue pack. Get sputum pot, deliver a sample and that is good.
- More people are becoming aware of Bronchiectasis and there is more information. Can't fault treatment in last 5 years. Husband with COPD brilliant respiratory nurses who good giving information and advice on self-care particularly around rescue packs.
- In relation to community services. Under Heartcare Walsall, referred to pulmonary rehabilitation but when went I felt sessions hard. Creating mental barrier. Respiratory Team Walsall Manor now doing video links which are good to keep an eye on you doing rehabilitation during this challenging period. Getting you to use upper part of chest and remove sputum which if sits to long can make it worse. Hospital rehabilitation has been good but during last 10 months feel gone backwards on this due to no physical interaction.
- Access rescue packs initially by GP but now by internet pharmacy. In last 12 months used 5 packs. I request through ECO then GP calls to say do you really need this. Respiratory nurse at hospital is happy with my use. For me when on the rescue packs do supply sputum sample. I do know when I am going downhill. I do wait at least 5 days before use. It is always when the weather goes damp.
- I have an Aerobika Machine with fan has been useful for me but not all service providers have these. The fan forces pressure deep down until bottom of lungs and if you do it in the morning it makes a huge difference.
- Point made that it has been good in these meetings to share information on techniques.
- Use the My GP app to get restocks and put in information to co-ordinate to one visit to pick up medication. Healthnet home care useful as with rescue pack particular during COVID has been difficult. You can say if do not need it its good.

5. In relation to GP access and Communication:

- I have not had a call from GP but no need if treatment elsewhere at Heartlands.
- GP practice is in a group and have been sending out letters but when ring GP surgery they know nothing about. Received a letter around self-care from palliative care centre but we

thought palliative care when were very worried.

- I have my rescue pack as it can take 14 days to get into GP. This was Pre COVID.
- GP during COVID have adapted and the telephone calls are good, do not always need to see the GP. Communication from St Peters Surgery has got better.

6.What could be delivered differently to support you?

- More use of social media set ups like these as I feel safe.
- More community Zoom settings with clinicians and the community-based team. They can still see me on Zoom.
- Used to be a breath easy group, for people to come together – Virtual Q&A sessions As I have not left the house for over 10 months. I have not had an attack in 10 months and previous to COVID I visited hospital over 15 times in 2 years.
- Or those who have severe long term health conditions virtual is the way forward and to get feedback from patients. This would also help with physical congestion at the hospital.
- Quite insulted that my husband's first appointment with his IPF at QE will be on the phone. Zoom and other platforms would be best. In normal times you would see consultant and CNS but one person over phone not ideal.
- Sharing experience with other online is also helping with mental health. Through this time the last place some respiratory patients want to go to is the hospital.
- A more integrated approach between the respiratory consultants / team and GP. An example I have COPD, Bronchiectasis I have also developed Type 2 Diabetes probably due to comfort eating when I feel down with my condition and due to inactivity. I have also developed AF. I have episodes when I am struggling to breath and dizzy. I do not know if it is the AF or COPD causing this. When I see my GP, he says it is my COPD. My AF has not been monitored for a while and I am unsure if I have or will get heart failure. I have been told I have stage 3 COPD. I

7.Thinking about interaction with services what do you think are working well?

- Community based Respiratory Nurses.

- I am under Manor not community team but get treatment through Heartlands and now self-administered. Zoom chats such as this are positive as they help others understand their condition.
- Working well, COPD Nurses in community good and visit now and again. Regular contact positive.
- Other patient said that the COPD nurses and community team a god send, before suggested by GP to be in the system I felt quite alone but as part of community service for Dad and given me reassurance. It is the people round the patient that also need support and condition understanding. Could always get through to a GP but now community service easier to access and do absolute upmost.
- Dad admitted only if he has had a serious infection, he has not had to go to hospital for check-ups etc. All have been done in the community. Did used to have a regular breathing test at the GP for peak flow but has not had it done. Not aware he could have this at home.
- Understanding your peak flow some patients found this useful to be done regularly.
- Only criticism as last occasion in hospital given Trimbo without a mask discharged and not used with mask. Many do not have access to all the same information. Saline for example helps to spit up mucus in the morning.
- Anything to help get mucus off chest would be helpful.
- Feel we are quite educated but many others are not. Dr Hudsey can communicate and with a great bedside manner to help patients understand their condition. An example from start told me everything and being honest.
- Difficult sometimes to access consultant due to waiting list.
- Understanding how allergies impact on conditions such as cold, pollution, damp, cold is important. Ok at home but when start moving around get worse. This in turn impacts on our lifestyle and weight gain.
- Attacks are really frightening and come with a vengeance. Community team are reassuring and if it were not for this I would end up in hospital. Anxiety is playing a big part and any support around helping with this would be useful.
- Impact on other health conditions not had blood tests for 9 months.
- Agreement that some patients are self-taught. Would like more training and to be more informed but is there capacity in the system. Would have liked more knowledge to question and challenge and know more details. However, some people do not want to know, and one size does not fit all.

- Using the internet has been a source for many but is this the best place. However, the BLF information is useful. www.BLF.org.uk and regular updating scientific evidence.
- During this period and prevalence of COPD going up. Question about capacity it has been a challenge in the system.
- Admitted into New Cross in 2019 they wanted to put me to sleep but they could not, I found it very frightening. Then transferred to Walsall Manor. Outpatient at Walsall Manor supported but the rehabilitation they over done me, and it knocked me for six.
- Heartcare Pulmonary rehabilitation positive and on a structured programme. Found is difficult getting the effort to get there. If not fortunate to drive it can be challenging. More information about accessing public transport. It puts people off.
- As a patient at Walsall Manor on the respiratory wards and intensive care, had to be ventilated in 2019. At time having thoughts its very distressing. Put faith in staff we must let staff take over. Care on Walsall Manor wards the specialist team was fantastic but staff on wards - poor communication I could not get toilet and incontinent after being laying in it for a few hours.
- But at Heartlands hospital kept up to date with treatment plan and kept up to date with care. Care at Heartland seems more joined up between inpatients and outpatients as outpatient clinic next to respiratory ward. This was however before COVID. Information from New cross to Walsall Manor was delayed and they did not seem to know much about me. The service between hospital and primary care do not seem to be joined up.
- Due to COVID and one Doctor practice but not been able to keep the appointment with nurses as she has been terribly busy. I rely on 6 months with nurse. Not known to community respiratory nurses. Have rescue pack months ago through the GP. If I get flair up or I'm bad I call the GP. Normally I can get through. If I had an exacerbation at weekend call Waldoc.
- Variation in knowledge. Each year I used to go to hospital as I have a Cpac, but not sent for some time. Never had anyone to know who to contact. This is helpful.
- What is the access to the service for those who do not know about Community Team? Getting access to it. I have even stopped and started my medication depending on how I have been feeling.
- More information and telephone numbers for advice and support with managing with a respiratory condition not just GP access. Provide opportunities for patients and carers access hints and tip of self-management. One patient in early stages COPD seem kept in the dark until access to Community Team.
- Even before COVID being part of a larger GP practice however when you can get through, they do action very quickly and get my dad in. It may be sign time, however every time my

dad must see another GP and must explain myself.

- Worry about medication as prescribed by GP and then hospital need to change medication, not seeing GP at moment to have in-depth check-ups. Worry if my medication is right for me. *Medicine management is really important.*
- I get really confused that there are so many different medications. It is great that I can call the respiratory team for advice and unfortunately, I do not seem to get much advice from my GP other than an annual Spirometry test. I must rely on the respiratory team, I think that there is too much emphasis on the respiratory team.

Appendix Two

Patient Stories

Respiratory Case Study -1

D is 79 years old and has COPD and dementia. Mainly due to the dementia she frequently called 999 (sometimes 3 times a week) and would be taken into A&E. From April 2018 to March 2019, she had 17 A&E admissions to Walsall Manor.

After MDT meetings around D's care involving the respiratory team In March 2019, she was moved into sheltered accommodation at OL. At the same time, she was also referred to the locality based Social Prescriber in West 2. The Social Prescriber arranged for her to attend Darlaston Town Hall (lunch club) and Darlaston Fellowship as she has previously lived in Darlaston.

This lady's admissions to A&E reduced to 6 from April 2019 to December 2019. She has not attended A&E since December. Moving to OL and the input from the social prescribing team has had a very positive effect on this lady that has resulted in greatly reduced A&E attendances.

She has been checked by the matron every 2 weeks and has 4 carers in a day. D called an ambulance as there was no other way to cope with her symptoms. This is the 6th or 7th time that D has been admitted into hospital in the last 12 months.

Previously D mentioned that she had not be heavily supported in how to manage her condition at home but has used her rescue packs and had to ask the GP for others. It is clear that social engagement and activity has helped this lady by focusing attentions away from just her conditions.

Respiratory Case Study - 2

JSS

Bentley Medical Centre

DOB 1956

In July 2019 JSS had visited her GP in Bentley after becoming more breathless for quite a considerable time. GP referred JSS to Walsall Manor for a spirometry test and had been diagnosed with COPD. JSS was not managing with the breathlessness very well and was taking steroid medication for exacerbation's sporadically when she felt exacerbation coming on.

JSS started to feel more poorly and was requesting steroids. She was able to get 4 packs of steroids without monitoring. JSS had been referred to the COPD community team but had not in the period of time had a community visit.

In Oct 2019 JSS was having breathing difficulties and after calling 999 was taken into Walsall Manor and onto the ITU ward with respiratory acidosis. JSS spent 5 days in ITU to manage the acidosis and to bring her breathing to a controllable rate.

JSS was discharged from hospital on the 25th of Oct 2019 and was referred again to the respiratory team in which the Community COPD Nurse visited JSS on the 26th of Oct. The COPD Nurse undertook bloods to get an overall picture and started to develop a management plan, explaining to JSS about using inhalers to their full capacity and exacerbation management.

JSS was referred to heartcare by the COPD team for a 12-week pulmonary rehab course which she found very reassuring and they were able to reassure her, examine, give advice on exercise and at the end her statistics had improved significantly.

Before JSS was struggling to do the basic housework and struggled to go upstairs. JSS is now able to get out and have a quality of life. She now understands medication and her condition and has also been able to get support through her GP to manage her anxiety which is linked to her condition management. The support and relationship with the COPD team has helped JSS significantly and she has said its the assurance that matters. Her family have also been advised to look for signs or worsening periods and when to call to get advice before starting any additional medication.

Respiratory Case Study - 3

SP

DOB 1950

S has severe COPD and was diagnosed 5 years ago. S is on oxygen 24 hours a day. Although S has a severe occurrence he does not have / need regular health visitors at home. One of the main challenges for S with his health condition is loneliness. S has not too long ago lost his wife who had Alzheimer's. S is impeded by his condition in relation to getting out and about mainly as the battery of the oxygen support will last just 2 hours. S visits the palliative care centre day centre regularly to socialise, talk to people. In explaining to us COPD can get you really down so social activity and talking to people really help, but also at the Palliative Care Day Centre they are trained, welcoming and supporting staff here.

The staff make a huge difference and are really helpful, encouraging and enthusiastic but remain professional. S explained that he has not had an exacerbation for 12months. S has not been given a rescue pack. S is though able to monitor his oxygen levels and use the support equipment well.

S knows that his condition will worsen over time. S is though disappointed that he never had a specific diagnosis nor discussions on if the condition worsens how this will impact on his life expectancy. S has been explained about an advanced care planning conversation within him but has decided that at the moment of capturing his story he declined the conversation.

Respiratory Case Study - 4

D's Story

D is 84 and lives in Darlaston, he has multiple health conditions including angina, quadruple heart bypass, bronchiectasis, arthritis, and fibromyalgia. D also has oxygen at night due to sleep apnoea.

D used to smoke but also worked in the steel mills in Willenhall for over 20 years where it was dusty and breathing in gases from hot metals. D tried to a course of exercise for pulmonary rehab but has found it too difficult as it was too painful, and this was impacting on his arthritis.

D has a really good relationship with his GP Dr Sina and is able to see the GP when needed and they are very accommodating.

D also has rescue packs for his COPD but with support from his wife only uses it when absolute necessary. D also only calls his COPD team when absolute necessary.

The challenge for D is twofold. He has many different appointments for each of his conditions but feels that there is little discussion between different organisations about how the conditions interlink.

D is in poor health but is happy with the level of care he receives but spends a great deal of time going to different appointments.

D used to access pulmonary rehabilitation at Walsall Manor but with his other deteriorating health conditions found this challenging and decided to withdraw from the support. He has been able to access effective pain management through his GP. He finds that the pain management is also a fundamental part of his respiratory management and finds that good pain management helps to reduce exacerbations.

Respiratory Case Study – 5

J's Story

J is 65 years old and lives in Beechdale. J has Bronchiectasis and was diagnosed with heart failure in 2018. J's conditions have been progressively getting worse. J has regular chest infections and dizziness thus he tries to limit the number of times that he goes out. One of the main challenges for J is he has found it difficult to come to terms with his condition.

This has affected his mental health considerably. During the pandemic J has had to self-isolate which he feels has made his condition even worse as he spends more time in the house on his own thinking about his conditions.

Although J finds his GP very helpful, he finds it difficult to understand if his symptoms of dizziness, shortness of breath and confusion are a result of his lungs or heart. J has been receiving support from the respiratory team in relation to advice, medication management and support. One of the vital elements of support from the community respiratory team has been around managing steroid use in chest infection management.

However, J feels that he has not had much support for his heart condition. His last two check-ups with the consultant have both been cancelled and his next appointment has been scheduled for March 2021.

J's likes attending to his allotment during the periods of better weather and has been offered support by other allotment members to care for his plot when he doesn't feel that he can maintain it.

Respiratory Case Study – 6

T's Story

T is 49 and has Asthma. She seldom visits her GP practice as she is usually fit and well. However, T had to attend the hospital A&E in October 2019 due to an exacerbation of Asthma which is normally well controlled. T was given nebulisers and a five-day course of Prednisolone 40mg and discharged.

She continued to feel unwell so went to see her GP in October 2019 due to issues unrelated to the asthma but was still wheezing so the GP made the asthma the priority and subsequently treated T for the asthma.

T felt exhausted and had resorted to sleeping sitting upright to ease her breathlessness and wheezing, her mobility had become restricted and she was experiencing pain in her neck, shoulders and back due to the constant coughing and struggling to breathe. T reported to her GP that she was not coping well with this episode both physically and emotionally and was also struggling to work full time and had no choice but to reduce her working hours.

The GP prescribed a further course of Prednisolone and advised her to see the Asthma Nurse who she saw in November 2019. The Asthma Nurse was so concerned at how unwell T presented with her breathing, that made an urgent appointment to see the GP the same day. T was prescribed a course of antibiotics.

In January 2020 T made another urgent GP appointment, and was advised she would be referred to a Respiratory Consultant / Team at the Manor hospital. T requested this referral

to be made as urgent if possible as she had already had 3 courses of steroids in 3 months with one visit to A&E and had been feeling unwell for four months by then and had been unable to sleep and sitting upright in bed.

T made another appointment to see the GP on the 15th of January 2020 due to struggling to breathe and was advised to make an appointment for spirometry and a referral to the Respiratory team at the Manor was made. T asked for this to be made as urgent but was advised it would be a routine appointment with no indication of when an appointment would be made available.

The GP advised that T made an appointment with for spirometry and this was made but with a health care assistant (HCA).

T was then told by the HCA that she could not have the spirometry as she had taken Seretide that morning (as directed by the GP). The spirometry took place. After the first attempt the result was poor and another attempt was made. T asked how many more attempts were required, and she was told, 'till we get the result we want' and it would be around six more attempts! She was also told that the Montelukast the GP had recommended was not effective and told me 'not to bother taking it.' The HCA said that she had looked at T's chest x-ray from February 2019 and that her lungs were in a 'terrible state' that this was indicative of the asthma not being managed properly. Furthermore, T was told the appointment with the respiratory team could take up to at least three months if not longer. The HCA also said being given a nebuliser regularly was very damaging for her heart.

T decided to see a private GP and advised of the history and of having had steroids prescribed four times over the past twelve months and unusually, having three episodes in a twelve-month period. T was advised that given her history in particular over the past three months that she needed to attend Urgent Care at the hospital immediately.

After attending A&E and three nebulisers later with limited effect, T was admitted for overnight observation and monitoring. The question of why she could not have a nebuliser at the GP practice was asked. The usual advice regarding the dangers of Asthma being potentially fatal was given, and that she needed to be treated in line with guidelines. They were concerned that the referral to the respiratory team was routine and not deemed as urgent when clearly, they were struggling to get it under control, and they were alarmed that I had been in this state now for over four months.

In summary,

- Should T have been referred to the Respiratory Team sooner?
- Concerns about medication management.
- The impact on anxiety and worry around the condition which inevitably exacerbates it.

- Feelings that support for Asthma patients is not at the same level of other respiratory diseases.

T made a formal complaint to her GP practice. The GP he agreed with all of T's concerns and was equally as concerned about her experiences and has reflected and stated that they should have telephone for an ambulance when T attended the surgery and should have referred her to respiratory as urgent and not routine. It was a constructive conversation, and the GP was very professional and reflective.