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An asthma patient passport could enable patients with severe asthma to get the right treatment when they present in accident and emergency with exacerbations

Using patient passports to improve A&E asthma care

In this article...

- › Why people with asthma may avoid accident and emergency
- › How an asthma patient passport can help
- › Details included in an asthma patient passport

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Abstract Newell K et al (2015) Using patient passports to improve A&E asthma care. *Nursing Times*; 110: 111, 15-17. The asthma patient passport (APP) is a patient-specific asthma plan that details what to do when asthma is out of control. It helps patients who have severe, difficult-to-manage asthma, and health professionals when these patients present at accident and emergency. This article shows that, while the APP acts as a patient's advocate, it also facilitates accessing emergency care by making it more streamlined. Case studies explore why people with asthma have avoided going to A&E, putting their lives at risk, and provide an insight into how difficult it can be for people to navigate the healthcare system when they are at their most vulnerable.

A recent national review of avoidable asthma deaths (Levy et al, 2014) reported that 1,200 people a year in the UK die from asthma. In total, 41% of asthma deaths occurred at home and 23% on the way to hospital, which indicates there is a continuing problem with asthma management.

The review authors made two key recommendations: for patients to have a personal asthma action plan; and for them to attend regular asthma reviews.

The British Thoracic Society and Scottish Intercollegiate Guidelines Network guidelines (2014) also advise these are good

practice.

Patient passport

An asthma patient passport (APP) has been developed to help both staff and patients who have severe, difficult-to-manage asthma when they present at accident and emergency. Before these patients used an APP, they would avoid attending A&E, which put their lives at risk.

The APP is a customised asthma plan that contains bespoke medical advice and actions to be taken when a patient's asthma is out of control.

It was created as a patient-centred product, and developed using a 360° design process that involved all those who would come into contact with the patient and their passport throughout their A&E journey.

Each APP is completed by the asthma nurse specialist (ANS) and the patient, and authorised by the asthma consultant physician. It folds down to the size of a credit card and fits into a purse or wallet.

This article includes three patient case studies to illustrate the patient experience of accessing emergency help with and without an APP.

Local context

All of the patients in our severe, difficult-to-manage asthma clinic are already receiving optimal medical treatment. They have an individualised asthma action plan and ongoing support from the clinic's multidisciplinary team.

However, we noticed that patients were avoiding going to A&E when they were having an acute, severe or life-threatening asthma attack. This put their lives at risk. The ANS met with patients to understand the reasons for this. The outcome of these meetings

5 key points

1 Many people die from asthma each year

2 People may have asthma exacerbations without wheeze

3 Having to answer the same questions in accident and emergency when breathless can be difficult and distressing

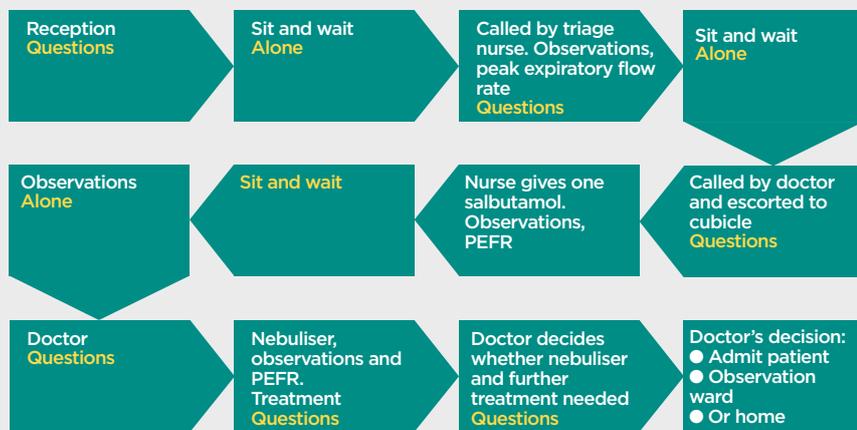
4 Delays in treatment for an asthma exacerbation can be fatal

5 Asthma patient passports can help patients receive timely treatment



The APP states that the patient needs urgent care and may be unable to talk

FIG 1. PROCESS MAP OF SELF-PRESENTING PATIENTS WITHOUT ASTHMA PASSPORTS THROUGH A&E



provided additional insight into the reasons why asthma deaths in patients with severe, difficult-to-manage asthma occur.

The APP concept

The concept of the APP emerged from meetings between the ANS, the allergy nurse specialist and patients with asthma. The patients explained that their experiences in A&E led them to actively avoid going there.

Although the patients were using their personal asthma action plans, a review of their emergency action plan found they felt there was an “awkwardness” about when and how to access emergency medical care. They were not taking appropriate action, even though they had agreed that this was a safe and sensible thing to do.

To try to capture the concerns and worries about going to A&E, the specialist nurses and patients decided to investigate by mapping their journey through emergency wards.

Developing the APP

Two process maps were developed; one follows the journey of patients self-presenting to A&E and the other tracks those brought in by ambulance. The maps provide a visual representation of patients’ experience in A&E and identify the discrete steps in the processes.

The process map for patients who self-presented at A&E (Fig 1) shows clearly that patients are being asked questions repeatedly at a time when they are too breathless to communicate their needs.

This adds to their feelings of being out of control and afraid. Details of individual asthma conditions are not taken into consideration by the healthcare staff, resulting

in treatment not always being escalated as quickly as it needs to be.

This issue was highlighted in Levy et al’s (2014) report, which shows that health professionals fail to recognise the signs of poorly controlled asthma and escalate treatment appropriately to initiate life-saving treatment.

As a result of the process mapping, the APP was developed. It aims to:

- » Ensure patients access emergency care in a timely manner;
- » Act as an advocate at a time when these patients are unable to communicate their needs;
- » Give information about the individual’s asthma, how it manifests and what treatment has previously worked to contribute to clinical decision making.

The ANS consulted with stakeholders, including A&E consultants, nurses and reception staff, and the asthma consultant physician. All were interested in the idea.

A representative from the London Ambulance Service said the passport could be helpful in information gathering and also for when patients present without a wheeze.

Effect of the APP

The APP achieved all its original aims and made the patient journey through A&E more efficient. Patients brought in by ambulance went through a 12-stage process before the APP was introduced. With the APP in place, there are now only nine steps.

Self-presenting patients also went through 12 stages before the APP was introduced and five afterwards (Fig 2). The APP has streamlined the process by:

- » Improving the flow through emergency care;

- » Reducing delays;
- » Ensuring treatment is individualised and right first time, thereby improving quality and lowering costs.

The streamlined process leads to correct and timely treatment, which can improve health outcomes.

As patients have a better experience, they are also more likely to access services in a timely manner and receive the correct treatment.

Case studies

Case study 1: “I do not wheeze”

Christeen Barnaby has had severe asthma all her adult life. Asthma care given by her GP enabled her to lead a fairly normal family life but her condition has worsened in recent years. Her two children have had to attend A&E regularly with her as she has had repeated, severe asthma attacks.

Ms Barnaby detested going to hospital so would wait until she was critically ill before attending A&E. She described how the hospital nurses and doctors would bombard her with questions to obtain her medical history, but she was always too breathless to answer. Staff would tell her: “We can’t treat you if we don’t know what’s wrong with you.”

Ms Barnaby’s children became her voice but, because they were minors, she said, staff would not listen to them.

Her daughter would tell staff repeatedly: “My mother is asthmatic and does not wheeze”, but they rarely took notice, saying instead: “It definitely is not asthma as she’s not wheezing.” Ms Barnaby says she would often pray that the staff would pay heed to what her children were saying but they rarely did.

In 2010, Ms Barnaby was referred to the severe asthma clinic and started treatment with omalizumab. As part of the process, she was reviewed by the ANS and became part of the group to receive the APP.

Describing the change this has made, Ms Barnaby reports that now when she goes to A&E she produces “my green passport” – the APP – which shows her medical condition, medical history and medical provider at a glance.

Ms Barnaby says: “I may not wheeze but I am asthmatic, and my asthma passport tells them so!”

Case study 2: “I now go to A&E”

Stacian Gilbert was diagnosed with asthma at the age of 10. She has severe brittle asthma, which means attacks can occur suddenly for no apparent reason. She is on step 4/5 of the BTS and SIGN guidelines (2014) for the treatment of asthma. Her

best peak flow is 400L/min when her asthma is well controlled. Since childhood, she has been in and out of hospital and A&E. She describes her experience as “not good as far back as I can remember”. Her life with asthma has been “very scary, especially after my dad died from an asthma attack at age 26”.

Ms Gilbert has experienced a number of asthma attacks over the past years and was very reluctant to attend A&E because she felt “unsafe, scared, isolated and ignored”. Once when attending A&E, she was asked to sit in the waiting area after being seen by the receptionist to wait for the triage nurse to call her. After the triage nurse called, she was told to wait again for the doctor to call her, even though she could not breathe and her chest hurt. Her peak flow recording was 200L/min on arrival; this was just half of her best reading of 400L/min, an indication of severe asthma. She realised she was very weak and could hardly speak or walk. She said: “I felt like I was going to die.”

Ms Gilbert struggled over to the resuscitation room and started banging on the door. She says: “I was shouted at to stop but I refused to because I knew that my lungs were giving up.” She collapsed; it was then the nurses realised something was wrong and she received treatment.

This experience was traumatic and caused her to stay away from A&E when she needed to attend. Since having an APP she now attends A&E if she needs to, according to her action plan. She now feels safe because her APP has become “my recognisable voice” – it answers all the routine demographic and medical questions. Ms Gilbert says she now receives effective treatment within the right timeframe.

Case study 3: “I’m too breathless to talk”

Janice Jones, aged 55 years, was diagnosed with brittle asthma in 2010. Due to the location of her home and workplace, she often had to attend different A&E units. These visits were frustrating and stressful, resulting in her avoiding them where possible. The process from presentation to treatment and admission was long and drawn out; the most distressing aspects included being asked the same questions over and over again by each clinician she saw. This happened when she was struggling to get sufficient air in to breathe, and needing to talk added to treatment being delayed, which could have put her at further risk.

Ms Jones describes the APP as “a life saver” as it speeds up treatment by acting as her voice. Her APP enables her to attend

FIG 2. PROCESS MAP OF PATIENTS WITH ASTHMA PASSPORTS SELF-PRESENTING



A&E and be confident she will receive the correct treatment rapidly, without having to repeatedly tell people her medical history. She has used the APP in A&E departments across the country, where it has been received with enthusiasm by clinicians.

In addition, Ms Jones’s regular medications are listed with a consultant’s signature on her APP; as a result of this, on one occasion while visiting her family in Sheffield, she was able to obtain urgently needed medication from a pharmacy using her APP.

Evaluation of the APP

The APP’s success is borne from the processes used in its creation, including the 360° development process that engaged all those who would come into contact with the patient and APP throughout their journey through A&E. This ensured that, while the patient remains the centre of concern, the APP works within existing systems. The 360° method of working was built up over time in the asthma clinic between patients and clinicians.

By ensuring engagement with all parties involved, the design process was improved with:

- » Easier framing of the problem to be resolved;
- » Clear objectives;
- » Feedback and troubleshooting;
- » Recognising the demands on clinical staff alongside the needs – both treatment and psychological – of patients.

Collaboration between patients and clinicians has had additional benefits beyond the projected outcomes of the study. Clinicians have gained a greater insight and understanding of the patient experience and are able to respond to asthma in a more holistic way. Patients have become experts in their condition, developing and demonstrating greater asthma

management strategies have led to improvements in health outcomes that were not set out in the project design.

Patients are also now actively involved in further service design changes within the clinic and also provide peer support.

In addition, the process of completing the APP has become a tool for aiding self-management, as it enables the ANS and the patient to discuss accessing A&E.

Conclusion

The process of creating and using the APP has highlighted how engagement of all relevant groups in the project design and development can ensure that project outcomes are met. It also has shown how working with patients as equal collaborators can improve their capacity to self-manage.

The APP has achieved more than its original purpose of helping clinicians to provide timely treatment, thereby ultimately saving lives.

In using the APP, patients and clinicians experience a simplified pathway for treatment that improves both health outcomes and clinician and patient confidence in the process.

Our work also adds to the findings of Levy et al’s (2014) report, and can help to improve care and reduce the risk of further asthma deaths. **NT**

References

- British Thoracic Society, Scottish Intercollegiate Guidelines Network (2014) *British Guideline on the Management of Asthma: a National Clinical Guideline. SIGN Guideline 141*. tinyurl.com/SIGNAsthma
- Levy ML et al (2014) *Why Asthma Still Kills: The National Review of Asthma Deaths (NRAD)*. tinyurl.com/WhyAsthmaStillKills

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