

# Story and response listing

### **About this report**

This report lists a selection of stories and responses published on Care Opinion.

It was created on 21 November 2019.

### Which postings are included?

This report shows stories in the **Care Opinion** subscription, which includes All stories.

The report is also filtered to show only All stories about NHS Ayrshire & Arran submitted on or after 01/01/2018 with a response

### Frequently asked questions

How do I find the original story online?

If you are viewing the report on a computer, you may be able to click the reference number to the right of the story. This will take you to the story online. If you are viewing the report on paper, you can find story number X online at: https://www.careopinion.org.uk/X

Why might a story appear more than once in the list?

Some stories are about more than one service. If so, the story will be listed under each service it is about.

### What do the story counts mean?

To the right of an organisation/service you will see a count. This tells you the number of stories listed in the report about that organisation or service (including any services run by that organisation/service).

#### What do the view counts mean?

The view count to the right of a story tells you the number of times the story has been viewed on Parameters!SiteName.Value by public users (excluding subscribers and the PO team).

#### Why might unexpected services appear in my report?

The services listed in the report depend on the stories that are included, and that depends on how you have filtered the report. So, for example, if you have filtered only according to where authors live, you may find they have used services some distance away.

#### **Sharing and reuse**

Contributors to Care Opinion want their stories to get to those who can use them to make a difference, so we encourage you to share these stories and responses with others.

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#### **About Care Opinion**

Care Opinion is a not-for-profit social enterprise which enables people to share the story of their care, and perhaps help care services make changes.

For more information, contact us via: https://www.careopinion.org.uk



Show/hide responses

This report lists 24 stories

NHS Ayrshire & Arran	24 stories
Ayr Hospital	2 stories
Combined Assessment Unit (CAU)	2 stories

### I was uncertain what was going to happen

464199

366 views

cepheusgb79 a service user 30/01/2018

I saw my GP and was sent to the combined assessment unit at Ayr Hospital for further assessment. I arrived at 5:20 and registered at reception. After that I waited 90 minutes in the waiting room without anyone coming to speak to me. I was uncertain what was going to happen and felt ignored - this added to my stress.

When I was taken through at 6:50 pm I met a nurse who took my blood pressure and heart rate but did not ask me how I was or explain anything to me. I was moved to the rapid assessment unit and sat in a cubicle but no-one spoke to me for a further 20 minutes until the on-call Doctor came in.

During that time I could hear the doctors and nurses discussing my case and other patients.

I would have liked to have been told what was going to happen in the unit when I arrived, who was going to see me, how long it would take etc., and kept informed at each stage which would have been put my mind at ease and helped me to relax.

In contrast, the specialty Doctor was very helpful, they gave me lots of time to ask questions and lots of information about my problem after completing their investigations. I left there after 3 hours. I was satisfied with the outcome of the investigation but I was not satisfied with the way I was treated in the Unit when I arrived (and I am still having trouble arranging a prescription with my GP).

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 31/01/2018

Dear cepheusgb79,

This is not what we want for our patients and I am so sorry this was your experience. You raise some very valid points and we are really keen to learn from your unfortunate experience. You are absolutely right, the unknown is a scary place to be and added to that - you were in hospital!! It helps us to cope when we understand what is happening.

I am sorry, I know we can't change your experience, but we can look into it and learn from it. I will pass this to the management team for their reflection but I also wonder if you would be so good as to contact me to enable us to look into the specifics of your case. I can be contacted on 01563 826222 and by email on [eunice.goodwin@aapct.scot.nhs.uk](mailto:eunice.goodwin@aapct.scot.nhs.uk)

On another note, I am glad you found the specialty doctor helpful and this will be shared with the team so your praise will not be over-shadowed.

I am not sure if I can help with the prescription, but if it is still an issue, I can try.

Thank you for taking time to give us this feedback,

Best wishes,

**Eunice** 

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 02/02/2018



Dear cepheusqb79,

I have been asked to post this on behalf of the Clinical Lead in CAU

"We apologise for your wait of 90 minutes unfortunately unscheduled emergency referrals to our department arrive throughout the day and we can't guarantee how long people will be required to wait.

I'm sorry that nobody explained prior to your arrival there may be a delay and we can ask GPs when referring patients to remind patients that we don't have a scheduled appointment system, and people may be required to wait before being assessed.

I'm disappointed that none of the nursing staff advised you they were checking your observations and then transferring you to our Rapid Assessment Area for review by our Consultant. I will ensure feedback is given to all staff about how you felt, in addition if you wish to discuss this with us further, please feel free to contact Eunice with your details and I, Leona Walker – Clinical Lead in CAU, will be happy to meet or contact you directly.

I'm glad you were able to be discharged after 3 hours and that you were happy with the communication from the doctor, again we will share this with staff.

Thank you for bringing this to our attention,

Kind regards,

Leona

Clinical Lead in CAU"

Best wishes,

**Eunice** 

#### cepheusgb79

Thank you for your responses.

I would appreciate if you would pass my experience on to staff so that other patients might feel better informed about what is going to happen when they arrive in the unit and less stressed while waiting.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/02/2018



Dear cepheusgb79,

We have made a change

Here is a wee update from charge nurse in CAU-

"Your experience was shared with staff at our staff forum on Wed 7th February with a very positive response on how to avoid this situation to improve our patients' experience at such an anxious time.

Following discussion within the clinical team there has been a few changes identified that may help in this situation, which we will implement immediately.

We aim to update GPs at the initial referral call and if there are delays, patients will aware before they arrive.

Our clerical staff at the front door will also be involved in updating patients on arrival if waiting times have lengthened.

Following this being highlighted previously, we designed posters for the waiting area to advise patients of long waits, what to expect and what will happen, I will review how these are placed, information on them, size etc. to assess any changes needed to ensure they are as helpful as possible".

Charge nurse is keen to reassure you that your experience has been listened to, widely shared and changes planned.

Best wishes,

Eunice



# We want proper care in our old age

542680

JohnnyK a relative 21/06/2018

1,199 views

In December 2017 my husband was called to Ayr Hospital for a scan following a bad chest infection. As he heard nothing he wrongly assumed that it was O.K. However, in mid January he was at Ayr Hospital for his routine bladder scope (he has bladder cancer) and a doctor looked at his notes and said he may have secondaries! Again nothing happened.

In February he had his birthday check with his G.P. I phoned Cathcart Street and spoke to Dr. McKenzie and said how worried I was about his scan. He then found that the scan in December had shown a shadow on his right lung, and was very worried that nothing had been done. Dr. McKenzie then organised an appointment at Crosshouse at the end of February. He confirmed that there was a shadow and he would need another scan and pulmonary function test. In April he has to go to 'on call' Dr at Ayr Hospital as he had a chest infection and feeling grim. Put on antibiotics.

We finally hear that my husband has to have a scan on towards the end of April at Ayr Hospital. We stupidly thought that this was for his chest but found out it was for the bladder area as Dr. Guran was wanting to check his pelvic area. When we phoned to see if this could have both areas scanned he was told this was not possible. However, a very sensible radiographer said there was no problem and did it.

We now move to May and I phone our surgery to ask why nothing is happening. They call us and get up the scan on the screen. The Doctor is very concerned and sends us to Ayr Hospital at noon. After 2 hours they start doing some tests, bloods, Xrays, etc. Our family arrive to give support. At 4.30pm a consultant doctor comes to hear our story and apologises. They have contacted urology and Crosshouse and say something should start to happen next week.

He gets a lung function test a week later at Ayr and a CAT scan at the Beatson at the end of May.

We return to see the Dr at Crosshouse in early June. As we enter the room the Doctor has not opened the file or put scan on the screen. After sometime they tell us the growth is bigger! They cannot find details of his pulmonary test and I tell them the date. Still can't find it. The doctor tells us that my husband will need a needle biopsy and depending on his fitness they could take part of the lung away. They said they will implement this and we should hear very soon.

In early June at Ayr my husband has an operation to look at his bladder, tube and kidney. The Doctor is optimistic that although in a mess it is not any worse. Bits taken for histology and my husband now bleeds and urinates every 20mins or less until mid June. Waterworks hasn't been right in 8 years but he copes and wears pads and rarely complains. Life is not easy but we accept our lot. I am just clear of breast cancer!

We both feel very alone and distressed that his condition has been left for all these months. He gets his results of urinary biopsy on July. This could have been at the end of June but we are having a holiday then and we've already cancelled one.

He has no complaints of Dr. Guran and the urinary department at Ayr. We are not looking for sympathy just proper care in our old age.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/06/2018



#### Dear JohnnyK,

We are preparing to make a change

Feedback is so important as it shines a spotlight on the things that go well and highlights things that have not. I agree entirely that you should get proper care as everyone should and I hesitate to say so, but I suspect these events are unrelated to age.

Our Assistant Director, John Swiatczak-Steele at Ayr Hospital, would like to look into this in order that we learn lessons from it. John will be very grateful if you would be kind enough to contact his office on 01292 614518, and give details such as your husband's name, address and date of birth.

Thank you so much for taking time to outline your husband's pathway and the failings within it. I am truly sorry that this has been both you and your husband's experience and we want to prevent it happening to others.

Kindest regards to you and your husband,

**Eunice** 

### John Swiatczak-Steele Assistant Director, University Hospital Ayr NHS Ayrshire and Arran 25/06/2018

Dear JohnnyK

Thank you for making contact with me today.

I have identified the appropriate manager to deal with your issue and I have asked that they contact you directly to ensure that we can resolve the outstanding concern we discussed this morning.

It has clearly been a distressing time for you and I can only apologise for the additional anxiety caused. It is extremely disappointing when things do not go to plan and I would like to understand and identify, as soon as possible, why this was the case for you so that I can ensure the correct systems and processes are in place to prevent from happening again.

Best wishes

John

John Swiatczak-Steele

Assistant Director of Acute Services, UHA



### **Respiratory Medicine**

1 story

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Urology 1 story

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Would recommend? (Friends and family test): Neither likely nor unlikely

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/06/2018



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Assistant Director of Acute Services, UHA

# **Ayrshire & Arran Community Services**

1 story

# **Community/District Nursing Service**

1 story

### Grandmother with reduced mobility

457239

201 views

concernedforlongtermwellbeing a relative 15/01/2018

Contact has been made numerous times in the past 6 weeks to the appropriate district nurse team, regarding a much needed preventative measure for my grandmother who now has reduced mobility due to her condition and has become more or less bed ridden.

Depending on her daily wellbeing and health my grandmother is now only able to be out of bed some days for up to 5-6 hours. The much needed airwave mattress to help prevent pressure sores I was told this afternoon, via an answering machine message, was that my grandmother does not meet the criteria so will not be provided an airwave mattress.

I feel that this is unfair and unacceptable as some days now my grandmother is unable to get out of bed and we fear for her skin integrity, she is unable to move around whilst in bed to alleviate pressure upon her bottom and sides, please advise.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 17/01/2018



Dear concernedforlongtermwellbeing,

I appreciate why you are concerned. It is difficult to be sure everything is as good as it can be when we are worried about someone at home that are less mobile. We want your gran to be protected too. I have spoken to the senior nurse for community in South Ayrshire and she will be happy to look into this for you. If you would you like to contact me I can arrange that for you. My contact details are phone - 01563 826222 and my email address is [eunice.goodwin@aapct.scot.nhs.uk] (mailto:eunice.goodwin@aapct.scot.nhs.uk). Thank you for raising this with us and giving us a chance to

help.

Best wishes,

**Funice** 

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 23/01/2018

Dear concernedforlongtermwellbeing,

We have made a change

Thank you so much for contacting me off-line. It is very heartening to hear that your gran now has the mattress. I am sure it will help. Once again, thank you for contacting us on Care Opinion and giving us the chance to help.

Best wishes,

**Eunice** 

#### 2 stories **Ayrshire Central Hospital Trauma & orthopaedics** 2 stories

# Walking is excruciating

529017

152 views

Vstar the patient 14/05/2018

truly don't understand this.

Still waiting! Guaranteed 12 week treatment stated in my letter from August 2017. Call each month to be told I'm very near the top of the list and should hear something soon, this has been going on since the end of Nov last yr I was told it would be Dec, Jan I was told Feb and so on. Now my foot is in such a bad state walking is excruciating. Life has been on hold as I don't want to be unavailable for a date and get put to the end of the list again. Now I have seen an article saying that orthopedic surgery is going to be cut..... I

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 15/05/2018

Dear Vstar,

I can't imagine how difficult this is for you. I am so sorry you are having such difficulties with both your foot and waiting time for an appointment It can be easy to take our mobility for granted.

I would like to look into this for you. If you want to contact me and provide details, please call me on 01563 826222 or buy email on Eunice.goodwin@aapct.scot.nhs.uk

Kind regards,

**Eunice** 

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/05/2018

Dear Vstar,

Thank you so much for contacting me. All the best for your operation, I believe that you now have a date.

Again, I am sorry you have had such a long time to wait but I am glad it is now in the foreseeable future.

best wishes,

**Funice** 



#### **Vstar**

Hi,

Yes, I have received a call today. Thank you so much for your help.

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Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 23/05/2018

Dear Vstar,

We have made a change

You are most welcome. I would love to take all the credit, but the Orthopaedic secretary was the real star here.

best wishes and good luck,

**Funice** 

# Lack of care for a broken hip

539595

Di321 a relative 14/06/2018

918 views

Contacting you is something that I would not usually contemplate as a means of complaining but I feel compelled to ask for your assistance or at the very worst to let you know that I feel that the NHS is failing to provide a service of care and compassion. My sister is in her fifties and has broken her hip. She fell late last year and it took 5 months of regularly visiting her local GP in pain until she was eventually sent for an X-ray via Ayrshire Central Hospital in May, only to be phoned by her GP two days later and told that she had indeed broken her hip. My sister works hard in her local supermarket and continued to work throughout this time, having been led to believe the pain was a muscular injury! She is also a widower, having lost her partner and father to her young son at the time, in around five years ago to a sudden and fatal heart attack. He was in his early forties. She has to work to earn a living but has been told under no circumstances by her orthopaedic surgeon at Crosshouse Hospital to work due to her broken hip and was subsequently signed off work by her orthopaedic consultant in May.

On the advice of her GP she was told to go immediately to Crosshouse Hospital last week due to severe swelling in and around the area of the broken hip, from her thigh to her buttock. She was told that the oncall orthopaedic surgeon would be waiting for her arrival. We spent 2 hours being sent from X-ray to the new ACU department onto A&E to eventually see a doctor who after waiting for 5 hours, eventually admitted her. She subsequently had an ultrasound where they established that the swelling was soft tissue oedema due to the damage caused by the broken hip. She discharged herself after two days having spoken to a doctor who told her nothing more could be done and to wait until her planned appointment with the orthopaedic consultant three weeks later. She still has severe swelling, very limited movement and can only move around the house with the aid of the zimmer that she was given in A&E. She lives in an upstairs flat with no lift and has stairs to her front door therefore rendering her a prisoner in her own home. She still cannot earn a wage and her house is now in jeopardy as she is struggling to pay her mortgage to keep a roof over herself and her son's. Her employer only paid her 2 weeks' pay and she is now relying on state sick pay. The doctor in A&E told us that her broken hip is not a life limiting emergency which in general terms is correct but her mental state at not being able to work, the worry over her financial affairs and the pain caused by living day to day with a broken hip is causing her mental angst and the family are becoming increasingly worried about her mental state as she tries to juggle bills and endures sever pain on a daily basis. Surely she can't be left to accept this? I have decided to turn to you for help on her behalf as she feels like she has tried every avenue and has given up. She has been told she will need surgery and a hip replacement but has been given no time scale for this to happen and there seems to be no sense of urgency meanwhile my sister's house is slipping out her grasp.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 19/06/2018



Dear Di321,

Some posts are just heart breaking to read and instil dismay. This should simply not be like this and I am so sorry for all the stress and distress this situation has caused your sister (and you).

I have no understanding of the detail here and we can't fully understand it without looking into it. I would most definitely like you or your sister to contact me so we can look into this and take it forward.

I thank you for bringing this to our attention, there is definitely work to be done here and we will do whatever we can to help your sister.

I can be contacted on 01563 826222 or by email at: eunice.goodwin@aapct.scot.nhs.uk.

Kindest regards,

Eunice

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/07/2018

Dear Di321,

We have made a change

Thank you for bringing this to our attention, and I am glad your sister contacted me off-line. I am pleased to say that your sister can now see the light at the end of the tunnel. She also understands what led to the situation. It has been a long haul and I am sorry that this was less-than optimal (I am sure there are other words to describe it too).

By way of explanation, not excuses, the main issue arose because a consultant was off sick and this clearly has a huge impact on delivery of service.

I would also like to mention (and thank) the secretary for all the work she has put into getting this resolution.

best wishes,

Eunice

#### **Crosshouse Hospital**

17 stories

# Staff not displaying name badges

491608

255 views

sigmaqg99 a service user 09/03/2018

I posted an opinion approx. 3 months ago about Porters name badges at Crosshouse Hospital (A&E/X-ray). I was back for a follow up appointment and noticed NOTHING had changed. I am very disappointed that no improvement- or change has happened despite what the response posted said. This is a simple, important part of front line staff clearly and visibly displaying who and what their name is. The #hellomynameis... ethos is around this concept, the cost is minimal and benefit to public/patients huge. I don't understand why NHS AAA hasn't adopted this for all staff?

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 15/03/2018

Dear sigmaqg99,

We are preparing to make a change

I passed this post (and a reminder of your previous post) to the senior management team for this area. The managers have agreed to look into the cost of this and time-scale for the provision of the badges.

I will post an update here when I have more information.

Once more, thank you for raising this with us. I am sure it will help many other visitors and patients too.

Best wishes,

**Eunice** 



#### Stoma Facilities in Disabled Toilets

510260

LoobyLoo2018 a service user 11/04/2018

334 views

I was at Crosshouse Hospital in Kilmarnock to visit an in-patient who was in a ward on the 4th floor. Shortly arriving in the ward, I had to leave to go to the toilet as my stoma had started to become guite active. There were no toilets on the ward for visitors. In fact, the only toilets were on the ground floor - which is some distance from the wards. By the time I got to the disabled toilet on the ground floor, I was now in desperate need to attend to my stoma. The disabled toilet is a large decent space, very adequate for people in wheelchairs, or those who require assistance. Unfortunately, in the disabled toilets, in this hospital, the needs of an ostomate have been completely overlooked. There is no shelf for you to lay out everything that you need to hand - fresh pouch, disposal bag, wipes etc. The toilet roll dispenser was extremely awkward to use - when you urgently need toilet paper, the last thing you want to do is to try and find the end of the toilet roll and then only be able to get a couple of squares before it breaks off and then you have to start all over again! There was no seat within the toilet so that if you required to change your underwear you could do so without having to use the toilet pan as a seat. After all of that, how to dispose of your disposal bag. There were 2 bins in the toilet - one clearly labelled for domestic waste and a sanitary bin. Unfortunately the opening of the sanitary bin was very small - obviously not designed to take anything larger than sanitary products. Can I also just mention the actual size of the sink? It's rather on the small side, and prohibits properly washing your hands thoroughly without water spraying everywhere!

I would like Crosshouse Hospital to address the needs of ostomates in all of their premises and within their disabled toilets, and also look at the provision of toilets for visitors to wards.

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/04/2018

Dear LoobyLoo2018,

We have made a change

How upsetting this must have been for you and  ${\rm I}$  am truly sorry for your distressing and unsatisfactory experience.

I would like to thank you so much for highlighting the drawbacks of the current facility at University Hospital Crosshouse. There is some good news. NHS Ayrshire and Arran are aware of the need to upgrade the accessibility toilet to reflect all needs, including those people with a stoma. Out estates management have plans drawn up; however we have some challenges to overcome. Possibly the next hurdle is funding. We also need to relocate staff from an existing area and all that goes with that. Then clearly all the usual things that go along with building works/ construction.

Estates and Management teams involved are exploring funding option at the moment. I suspect this will unfortunately, not be resolved quickly but it is firmly on our agenda. I was wondering if you would be interested in being involved as one of our expert consultants when we are further along with the design stage. If you would like to help us ensure this suits the needs of people with a stoma, please drop me an email or call me with your contact details. I will pass them to the senior manager responsible for the development and we can 'use your expert opinion' when we at that stage.

I would also like to thank you for educating me with a new word. In my NHS working years, too many to confess to, 'ostomates' it is not a word I had come across.

I hope this is helpful although I appreciate this will not be resolved in the short term and does not address all your suggestions.

\*\*One thing we have done\*\*

We have changed the bin for a clinical waste bin which has a much wider opening at the top and therefore it will help with waste disposal.

Best wishes,

**Funice** 

LoobyLoo2018



### Hi Eunice,

Thank you for your response. I fully understand that changes to the facilities won't happen overnight due to various reasons, but I'm happy to learn that this will now be addressed. I would like to be involved as things progress, and can I suggest that the Stoma Nurse Team at Crosshouse also be involved too? Together we could ensure that appropriate facilities are available for ostomates. Sometimes a small change can make a big difference! The word ostomates is an umbrella term for those with a colostomy, urostomy or ileostomy - I hadn't heard of it myself until I saw it at the Colostomy Association. Perhaps they also can offer some help - I know that they have helped Sainsbury address the stoma/disabled toilet issues as well as some other large organisations. Thank you again, and I will be in touch with my contact details.

#### LoobyLoo

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 16/04/2018

Dear LoobyLoo2018,

Thank you, yes, I believe the stoma nurses will be involved. I confess I did Google the term ostomates. I thought it was a great name myself.

Thank you for agreeing to be in touch and giving your expert advice, I am sure all the help we get will bring the facilities to the standard required.

Thank you so much for being in touch,

Take care.

**Eunice** 

# Waiting times for breast clinic referral

Marmite67 the patient 06/06/2018

My GP made an urgent referral to the Breast Clinic for me 2 weeks ago saying that I would be seen within two weeks. When no appointment arrived this morning I phoned the surgery who gave me the number for Crosshouse hospital and told me to speak to appointments. The lady in Appointments was very pleasant but explained that the current wait for URGENT appointments was 2 to 4 weeks.

I've been in a high level of anxiety for the last two weeks so to be told I may have to wait ANOTHER two weeks just for an initial appointment is extremely distressing. I don't have any constructive suggestions to improve the situation apart from the obvious. I just felt that the impact of missing waiting time targets should be highlighted.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 18/06/2018

537407

676 views



#### Dear Marmite67,

We are preparing to make a change

I am sure this must be a very distressing and worrying time for you and I am sorry you are waiting longer than you were advised initially. I am sure you will have done so, but just in case you haven't, If you can be free to attend at short notice, please let the appointments team know. If there is a cancellation, you could possibly benefit from being seen earlier.

I appreciate that your anxiety will be high but I suspect we have increased your anxiety by giving you the expectation that your appointment would be within two weeks. Again, may I say how sorry I am for any additional distress caused to you. In order to address the misinformation aspect of this, we are exploring how to reduce the possibility of this happening again.

I know this will be of little comfort for you while you wait, but it I hope it is helpful.

I do hope you get your appointment soon and everything goes well,

best wishes,

Eunice

#### Marmite67

Thank you for your response. I now have an appointment to see the consultant, 5 weeks after my urgent referral and yes I did let the hospital know I was available for cancellations.

I agree that it is about expectations. I incorrectly expected that the service from NHS Scotland would be comparable with that in England and Wales where I believe the target time for an urgent referral to be seen is 2 weeks. I was unable to find the target times in Scotland as referenced in "Scottish Referral Guidelines for suspected cancer" dated May 2014, so perhaps so they can not be quoted or referenced. The only guidance appears to be that the wait should not be "too long" according to the Patients Charter of the same date.

Perhaps as part of your review you could look at renaming the referral to 'priority' rather than 'urgent' as the latter implies a sense of immediacy according to the dictionary definition. Alternatively a perhaps more radical approach would be to take steps to reduce the waiting time and thus expectations would not need to be managed.

I hope that should I be diagnosed with breast cancer in coming weeks that my expectation of starting treatment with the target 62 days of referral will not need to be further managed.



### This experience has left my father worried

bam a service user 08/05/2019

Over the last 4 weeks, I've been to Crosshouse Hospital almost every day, taking an elderly relative to visit a family member. I've also taken my father to an outpatient appointment during this time.

I've found it impossible to find a parking space almost every single day. When taking elderly people to the hospital, being able to park is a necessity.

On the day I took my father to his appointment, we were unable to find a parking space on time. He has severe mobility problems and is a Blue Badge holder. He also has issues with his memory and getting confused easily. I am his full-time carer.

We tried the disabled car park near the front entrance but it was full. At least 3 cars parked there were not displaying Blue Badges. Several other cars were clearly using the disabled car park as a drop off/collection point, taking up parking spaces.

My father had to get out the car on his own and struggle to walk into the hospital on his own while I spent a further 10 minutes trying to find a parking space. I finally managed to park in a small carpark at a smaller building separate from the main hospital building. When I caught up with him inside, he was a little upset as he had difficulty finding the correct waiting area on his own.

I found the same problem with parking almost every day while taking my elderly relative to Crosshouse Hospital over several weeks. We noticed that the car park was half empty on bank holidays over Easter. Whether this is because less staff work on these days or no outpatient clinics are held on these days, we don't know, but it does suggest that something could be done to alleviate parking problems.

This experience has left my father worried about attending appointments in future, and I really feel that action of some sort should be taken to try and sort this problem out.

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/05/2019

Dear bam,

It has been so difficult and stressful getting parked for your father's appointments and I am so sorry.

I suspect you are right, easier parking over Easter was probably a bit of both; staff off and less clinics.

I would like to thank you for raising this. I also sympathise with those who do not have a blue badge but due to a condition - at that moment in time, they are unable to walk far.

I will pass your comments to those responsible for the car park for their refection and I will report back here if there are any actions proposed as a result of this situation.

I hope your father is well on his way to recovery,

Best wishes,

Funice

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 27/05/2019

654384

235 views



Dear bam

We are preparing to make a change

Here is an update which I hope will go some way to address your concerns about the parking situation at Crosshouse Hospital.

There are two proposals to alleviate the car parking issue at Crosshouse Hospital. Firstly, there is approval for an additional 100 car parking spaces and this is currently in the scoping/planning phase.

We are also in the process of seeking approval to transfer management of the 'Disabled' Car Parking spaces to the Ayrshire Roads Alliance, which would mean that Ayrshire Roads alliance would manage the appropriate usage of the spaces as NHS Ayrshire and Arran have no legal rights to enforce the law regarding parking in blue badge spaces.

Best wishes,

**Eunice** 

#### bam

I am pleased that the issue of misuse of disabled parking spaces is being taken seriously and that steps are being taken to deal with it. I am also glad to hear that there are plans to build much needed parking spaces. I will tell my Dad this good news.

Thank you, Eunice, for taking the time to look into this matter and reply to me. It means a lot that the needs of people with mobility problems, like my Dad, are being considered and taken into account.

On a final note, since I noticed this parking problem, I've decided that (although I need to use the car for my Dad's appointments) if I should ever have to attend an appointment at Crosshouse Hospital for myself, then I'll use the bus instead of taking up a parking space that someone else might need more than me.

### **Accident & Emergency**

5 stories

1.129 views

Rude Staff 524045

Disgruntledbuthumoured a relative 03/05/2018

Dad punctured his foot on a plug, funny I know, I dressed the wound and it eventually stopped bleeding. My dad still had pain and swelling and tingling so rang NHS 24 for advice, wasn't sure if we should bother with A& E but NHS24 were worried about the type of pain and whether he'd need antibiotics so advised him to attend.

The department was dead being a Tuesday night and not a lot happening, staff confirmed this and told us they had no one else to see but then left us in a room for an hour & a half with no communication about what we were waiting for and to be honest, if the nurse thought it was fine she has the authority to say I think that looks okay go home.

Instead the grumpy, hacked off doctor arrived and asked my dad what was wrong, my dad told him and then the doctor went so why are you here like so? We felt that the doctor was actually quite rude, didn't smile once or acknowledge that we just came to check it out and the department wasn't busy so what was the problem. Then when we left not so much as a smile or a goodbye.

I understand ED doesn't like time wasters but was all innocent and just and NHS 24 send us in. Just plain rude service. Next time talk to your patient and smile instead of chatting outside the whole time whilst ignoring us completely for the time being. We weren't looking for special treatment we just wanted someone to say it's fine go home, didn't really need a doctor given the nurse sees these things all the time. Maybe structure your service to be more nurse led and more assertive.

Claire Gilroy Specialty Doctor NHS Ayrshire and Arran 03/05/2018



Dear Disgruntledbuthumoured,

Thank you for taking the time to send us your feedback. I am sorry that your dad and yourself did not receive the level of patient centred care that we expect our staff to deliver in our department.

I think we can learn a lot from your experience and I will ensure that your feedback is shared with our whole team. Communication, in many ways, is the most important part of what we do and you have given several examples of how we could potentially improve this.

Once I discuss this with my team I will be back in touch. In the meantime, if you would like to discuss this further please contact me [Claire.gilroy@nhs.net](mailto:Claire.gilroy@nhs.net)

I hope your dad is feeling better.

Claire

#### Shona Lawrence Patient Experience Manager NHS 24 04/05/2018

Ηi

Thanks for sharing your story. Your Dad's injury sounds painful, so I do hope he is doing much better.

Your story has been tagged by the Care Opinion Team to NHS 24 as you mentioned contact with us which resulted in your Dad being advised to attend A&E. Your experience of A&E doesn't sound great, however I am pleased to see that Claire, my colleague from NHS Ayrshire & Arran, has responded to you.

If there is any specific feedback you wish to provide for the NHS 24 part of your Dad's care, then I would be delighted to hear from you. I can be contacted on 0141 337 4597 or by email at [patientaffairs@nhs24.scot.nhs.uk] (mailto:patientaffairs@nhs24.scot.nhs.uk)

Thanks again for sharing your story and I do wish you both well.

With kind regards

Shona

Shona Lawrence

NHS 24 Patient Affairs Manager

Claire Gilroy Specialty Doctor NHS Ayrshire and Arran 10/05/2018



Dear Disgruntledbuthumoured,

We have made a change

Negative feedback is always difficult to hear but we know that we can use it to help us to improve. I therefore want to thank you once again for taking the time to tell us about your experience in our department.

On Thursday, I circulated your feedback to all of our medical staff by email and then handed out copies to all of our staff at our team huddle the following day. This led to multiple conversations centring around effective communication.

As a team, we would like to ensure that all patients and their relatives have a positive experience in our department. We know that to achieve this effective communication is necessary at all times. Communication skills encompass more than just the words we speak and, as you pointed out, sometimes non-verbal communication skills like smiling and eye contact are just as important. These skills need to be developed but even the most effective communicator can be challenged by the environment we work in; stress, pressure, tiredness can all contribute to a poor consultation.

Today, on bank holiday Monday, we asked our team to think about what we can do to improve communication and asked them to write their ideas up on a board. We then asked them to pledge what they would personally do to help the team achieve this over the coming weeks. We received 16 different personal pledges ranging from role modelling and challenging negative behaviour to updating patients and relatives about waiting times. I am hopeful this will lead to improved patient and staff experience.

Claire

'We all need people who will give us feedback. That's how we improve' Bill Gates.



### Lack of care for a broken hip

Di321 a relative 14/06/2018

539595

918 views

Contacting you is something that I would not usually contemplate as a means of complaining but I feel compelled to ask for your assistance or at the very worst to let you know that I feel that the NHS is failing to provide a service of care and compassion. My sister is in her fifties and has broken her hip. She fell late last year and it took 5 months of regularly visiting her local GP in pain until she was eventually sent for an X-ray via Ayrshire Central Hospital in May, only to be phoned by her GP two days later and told that she had indeed broken her hip. My sister works hard in her local supermarket and continued to work throughout this time, having been led to believe the pain was a muscular injury! She is also a widower, having lost her partner and father to her young son at the time, in around five years ago to a sudden and fatal heart attack. He was in his early forties. She has to work to earn a living but has been told under no circumstances by her orthopaedic surgeon at Crosshouse Hospital to work due to her broken hip and was subsequently signed off work by her orthopaedic consultant in May.

On the advice of her GP she was told to go immediately to Crosshouse Hospital last week due to severe swelling in and around the area of the broken hip, from her thigh to her buttock. She was told that the oncall orthopaedic surgeon would be waiting for her arrival. We spent 2 hours being sent from X-ray to the new ACU department onto A&E to eventually see a doctor who after waiting for 5 hours, eventually admitted her. She subsequently had an ultrasound where they established that the swelling was soft tissue oedema due to the damage caused by the broken hip. She discharged herself after two days having spoken to a doctor who told her nothing more could be done and to wait until her planned appointment with the orthopaedic consultant three weeks later. She still has severe swelling, very limited movement and can only move around the house with the aid of the zimmer that she was given in A&E. She lives in an upstairs flat with no lift and has stairs to her front door therefore rendering her a prisoner in her own home. She still cannot earn a wage and her house is now in jeopardy as she is struggling to pay her mortgage to keep a roof over herself and her son's. Her employer only paid her 2 weeks' pay and she is now relying on state sick pay. The doctor in A&E told us that her broken hip is not a life limiting emergency which in general terms is correct but her mental state at not being able to work, the worry over her financial affairs and the pain caused by living day to day with a broken hip is causing her mental angst and the family are becoming increasingly worried about her mental state as she tries to juggle bills and endures sever pain on a daily basis. Surely she can't be left to accept this? I have decided to turn to you for help on her behalf as she feels like she has tried every avenue and has given up. She has been told she will need surgery and a hip replacement but has been given no time scale for this to happen and there seems to be no sense of urgency meanwhile my sister's house is slipping out her grasp.

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 19/06/2018

Dear Di321,

Some posts are just heart breaking to read and instil dismay. This should simply not be like this and I am so sorry for all the stress and distress this situation has caused your sister (and you).

I have no understanding of the detail here and we can't fully understand it without looking into it. I would most definitely like you or your sister to contact me so we can look into this and take it forward.

I thank you for bringing this to our attention, there is definitely work to be done here and we will do whatever we can to help your sister.

I can be contacted on 01563 826222 or by email at: eunice.goodwin@aapct.scot.nhs.uk.

Kindest regards,

**Eunice** 

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/07/2018



Dear Di321,

We have made a change

Thank you for bringing this to our attention, and I am glad your sister contacted me off-line. I am pleased to say that your sister can now see the light at the end of the tunnel. She also understands what led to the situation. It has been a long haul and I am sorry that this was less-than optimal (I am sure there are other words to describe it too).

By way of explanation, not excuses, the main issue arose because a consultant was off sick and this clearly has a huge impact on delivery of service.

I would also like to mention (and thank) the secretary for all the work she has put into getting this resolution.

best wishes,

**Eunice** 

# Worrying inconsistencies in discharge letter

542674

DP123 the patient 20/06/2018

262 views

After being taken in to A&E with tachycardia, the staff were great and looked after me and ensured that I was alright. I was later taken to a ward when my symptoms had settled down. I had history the event conversation with the nurse and then about 3 hours later the doctor, who mentioned an Echocardiogram and a tape to monitor my heart. I was placed on telemetry at seven in the morning and had my abs taken. Perfectly good and reasonable. When the consultant came in to see me that morning, they mentioned that I might go on to beta blockers which I want keen on as my resting HR is normally 50, so this could potentially put my pulse at a dangerously low rate for normal function. When I looked at my discharge letter it said that I had refused a 24 hr tape and a bp monitor. This is untrue. I mentioned that I had a private consultation booked in Glasgow, but never refused anything other than being unseen to start a drug regime. It also stated that I was on over night telemetry, again this was not true. I have to take this letter addressed to my GP to my GP and to my consultant, which looks like I have been uncommitted to any sort of investigation. The fact is that these were never offered to me. I was basically discharged from the hospital with nothing other than I had sinus tachycardia and told not to drink so much coffee. This is very disappointing from the consultant who seen me this morning, when all the other staff were brilliant

[Unsure about 'Explanations']

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 21/06/2018

Dear DP123,

I am sorry you were disappointed with these aspects of your care. I wonder if it would help to have some clarification by one of the cardiology team and give us the chance to rectify any errors in your letter. If you would us to do this, can you please contact me by email on [eunice.goodwin@aapct.scot.nhs.uk] (mailto:eunice.goodwin@aapct.scot.nhs.uk) or call me next week on 01563 826222 as I will be away from the office until Monday.

I am sure we can resolve this for you to your satisfaction,

Best wishes,

**Eunice** 

We are preparing to make a change



### Receptionist with attitude

615364

funnyax55 the patient 14/01/2019

304 views

On Wednesday I had to go to Crosshouse Hospital A&E as I was feeling very unwell. On Thursday when I was discharged the receptionist on the main desk was very unhelpful. I asked if I could have a taxi called for me as I had no other means of transport, I was made to feel as I was just too much trouble, they huffed and puffed about calling a taxi.

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 14/01/2019

Dear funnygx55,

a change

We have made

What a shame. It is never nice to hear about poor customer care and it must leave a bitter taste too.

Not only is this disappointingly poor 'customer care' however there is also a lack of knowledge. There is an 'info point' in this department where you can call a taxi free of charge. There are also a few other phone numbers on this 'info point', one of which is a direct free phone line to Care Opinion (there is a bit of irony there I am sure). I know this as I was instrumental in this being installed in the waiting room.

Sadly, an experience like this can over shadow excellent care and it can be the thing we remember and 'take home'.

I will share this with the team for their reflection. I am sure it will be discussed at the huddle and also awareness raised to the 'info point'.

Thank you for raising this with us. not only can we learn from this, but it is also easily rectified with knowledge and reflection.

best wishes,

**Eunice** 

647288

KG87 a relative 10/04/2019

**Inconsistent Care** 

1,041 views

My husband attends A and E and usually the Combined Assessment Unit a couple of times a year due to complications of his auto-immune condition. Every time he receives different care, protocols and faces differing levels of knowledge of his condition.

This culminated on the most recent occasion in medication being withheld despite him repeatedly asking to see a doctor to discuss this as he understands his condition isn't common and not generally well understood. He felt frustrated and quite scared. Such a disappointment after an amazing care experience when I gave birth to my son last year.

We are apprehensive about our next admission now!

### Claire Gilroy Specialty Doctor NHS Ayrshire and Arran 11/04/2019

Dear KG87,

I am really sorry that your husband felt frustrated and scared during his most recent admission to hospital. Auto-immune conditions can be rare and as you point out this can lead to varying levels of knowledge. When you are dealing with a condition that can result in multiple hospital admissions the last thing we want you to feel is apprehensive.

It can sometimes be useful to create care plans that are agreed with the specialist and can be shared with the patient, the receiving doctors and the emergency department team. This may be useful in your husband's case. If your husband would like to discuss this with me then if he sends me his name, date of birth and contact telephone number to [Claire.gilroy@nhs.net](mailto:Claire.gilroy@nhs.net) I will arrange a meeting.

Claire



### Claire Gilroy Specialty Doctor NHS Ayrshire and Arran 19/06/2019

Dear KG87,

We have made a change

I really enjoyed meeting with you and your husband a few weeks ago. It really did show the power of feedback as it has allowed for learning across our system. Thank you for agreeing to allow me to place an update on Care Opinion.

Following your post and our meeting a number of things have happened;

- 1. We have placed a copy of your care plan on our A&E system and are looking at ways to place this in your notes in the medical unit. You have a paper copy of this so that you can present it if you ever require to.
- 2. A number of our team attended a local training session delivered by your consultant on dealing with endocrine emergencies.
- 3. Your consultant has agreed to come and give some teaching to the A&E doctors. We are hoping this will take place at one of the joint meeting we hold with our medical colleagues.
- 4. I am going to place a teaching note on our 'One Minute Wonder' board which will be there for 2 weeks and will share this post together with how to deal with similar patients in an emergency situation. I will share this with you and your husband prior to it being placed on the board.

Many thanks for taking the time to help improve care for all of our patients. We really appreciate all of your input into the above projects.

Claire

Cardiology 1 story

### Worrying inconsistencies in discharge letter

542674

*DP123* the patient 20/06/2018

262 views

After being taken in to A&E with tachycardia, the staff were great and looked after me and ensured that I was alright. I was later taken to a ward when my symptoms had settled down. I had history the event conversation with the nurse and then about 3 hours later the doctor, who mentioned an Echocardiogram and a tape to monitor my heart. I was placed on telemetry at seven in the morning and had my abs taken. Perfectly good and reasonable. When the consultant came in to see me that morning, they mentioned that I might go on to beta blockers which I want keen on as my resting HR is normally 50, so this could potentially put my pulse at a dangerously low rate for normal function. When I looked at my discharge letter it said that I had refused a 24 hr tape and a bp monitor. This is untrue. I mentioned that I had a private consultation booked in Glasgow, but never refused anything other than being unseen to start a drug regime. It also stated that I was on over night telemetry, again this was not true. I have to take this letter addressed to my GP to my GP and to my consultant, which looks like I have been uncommitted to any sort of investigation. The fact is that these were never offered to me. I was basically discharged from the hospital with nothing other than I had sinus tachycardia and told not to drink so much coffee. This is very disappointing from the consultant who seen me this morning, when all the other staff were brilliant

[Unsure about 'Explanations']

Would recommend? (Friends and family test): Neither likely nor unlikely

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 21/06/2018



Dear DP123,

We are preparing to make a change

I am sorry you were disappointed with these aspects of your care. I wonder if it would help to have some clarification by one of the cardiology team and give us the chance to rectify any errors in your letter. If you would us to do this, can you please contact me by email on [eunice.goodwin@aapct.scot.nhs.uk] (mailto:eunice.goodwin@aapct.scot.nhs.uk) or call me next week on 01563 826222 as I will be away from the office until Monday.

I am sure we can resolve this for you to your satisfaction,

Best wishes,

**Funice** 

### **Combined Assessment Unit (CAU)**

2 stories

Inconsistent Care 647288

KG87 a relative 10/04/2019

My husband attends A and E and usually the Combined Assessment Unit a couple of times a year due to complications of his auto-immune condition. Every time he receives different care, protocols and faces differing levels of knowledge of his condition.

1,041 views

This culminated on the most recent occasion in medication being withheld despite him repeatedly asking to see a doctor to discuss this as he understands his condition isn't common and not generally well understood. He felt frustrated and quite scared. Such a disappointment after an amazing care experience when I gave birth to my son last year.

We are apprehensive about our next admission now!

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Claire

Claire Gilroy Specialty Doctor NHS Ayrshire and Arran 19/06/2019



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Following your post and our meeting a number of things have happened;

- 1. We have placed a copy of your care plan on our A&E system and are looking at ways to place this in your notes in the medical unit. You have a paper copy of this so that you can present it if you ever require to.
- 2. A number of our team attended a local training session delivered by your consultant on dealing with endocrine emergencies.
- 3. Your consultant has agreed to come and give some teaching to the A&E doctors. We are hoping this will take place at one of the joint meeting we hold with our medical colleagues.
- 4. I am going to place a teaching note on our 'One Minute Wonder' board which will be there for 2 weeks and will share this post together with how to deal with similar patients in an emergency situation. I will share this with you and your husband prior to it being placed on the board.

Many thanks for taking the time to help improve care for all of our patients. We really appreciate all of your input into the above projects.

Claire

### Noisy during the night

665767

matarzr98 a service user 12/06/2019

277 views

Referred by GP following suspected stroke.

Assessed at the CAU, University Hospital Crosshouse. Impressed by the curtesy and efficiency of staff.

Admitted to ward 3E where I continued to be impressed by the curtesy and efficiency of staff.

The ward was very noisy throughout the night so got little sleep. While a lot of this is unavoidable, due to it being a high dependency unit, some thought should be given to reducing the noise and disturbance during the night.

### Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 12/06/2019

Dear matarzr98,

Thanks very much for taking the time to post your feedback on care opinion. It is great to hear that you found staff to be efficient at all stages and respectful of your needs. The staff will be delighted to read this and I will ensure this is shared with them.

Coming in to hospital with a stroke is a frightening time and rest is so important as part of recovery. Although the ward is a high care area with monitors that alarm and a lot of activity there is no doubt we need to ensure that we reduce avoidable noise. You are right to highlight this and I will ensure as a team we look at ways to reduce noise overnight.

We are currently looking at getting an area within the unit where patients can be assessed for thrombolysis (clot buster) out with the 6 bedded area. We hope this would then reduce some of the noise. We very much appreciate your feedback and I will remind staff to minimise noise and look at any other ways to do this.

I hope you are now recovering well

Best wishes

Christine

Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 08/10/2019



Dear matarzr98,

We have made a change

Following your feedback we have piloted using ear plugs and eye masks for appropriate patients. This has proven very effective with patients describing them as a "godsend". Your feedback has been at the heart of the change and has already made a difference to a number of patients.

Within a high-care 24/7 receiving unit I can only imagine how noisy it must be and how this would have a negative impact on your experience. Through your sharing your experience on Care Opinion we have been able to enhance patient experience.

We now have ear plugs and eye masks available for all suitable patients.

Thank you,

Christine

**Dermatology** 1 story

# Great service from the consultant ..but... seriously inefficient

462142

1,194 views

Left the building the patient 24/01/2018

Arrived for a 10.45 appointment to be told the consultant was already at least an hour behind - even though it was fairly early in the day. Eventually invited in almost 90 minutes late. Then sent to another area to discover they were closed for lunch. The original area - who sent me there- said they didn't realise that as they had no idea how that area operated. It was suggested that, although they sent me there, I phone later to make an appointment - it seems there is no internal process for cross referral- and everything stops for lunch.

I had already rearranged two business appointments during my initial delay, so rearranged again and sat and waited to be seen. It seemed the course of least resistance.

My point is this - the consultant was excellent - the next professional I saw was excellent- but what an inefficient way to run a business. Please give people appointment windows that mean a consultant is not so far in arrears with their time so early in the day. It also shows respect to the patient.

Introduce a joined up internal cross referral system which offers a smooth, trouble and worry free transition for the patient. My morning and early afternoon could have been less frustrating if simple internal processes were evident.

Would recommend? (Friends and family test): Don't know

Sandra Hanlon NHS Ayrshire and Arran 24/01/2018



#### Dear Left the Building

We are preparing to make a change

Firstly, can I offer my sincere apologies for the clinic running late? The patients seen at the earlier appointments at clinic can sometimes be more complex than they appear which takes the Consultant more time which then has a knock on effect. I agree that the length of time of your delay was frustrating but glad that once you were seen that it was a positive consultation.

The current system of sending patients directly from clinic to Medical Photography is to eliminate the need for a return visit if this suits the patient. I would like to look into your experience of being sent to Medical Photography at the lunch time period to see if this was a one off due to exceptional circumstances or if this is a regular occurrence. I would be extremely grateful if you could contact me on 01563 827923 to allow me gain additional details so I can investigate this further in the hope that we can prevent this happening again.

Thank you for highlighting the issues you encountered, I will also review our systems to see if alterations can be made to ensure smoother running of our clinics.

Please be assured that your story will be shared with the wider team to improve the service and care we deliver.

Kind regards

Sandra Hanlon

**Dermatology Senior Charge Nurse** 

# Ear, Nose & Throat

# Long awaited ENT Consultation seemed futile

542078

831 views

ELHell a parent/guardian 19/06/2018

After waiting five months for an appointment for my five year old daughter we were given 15 minutes of the consultants time and told we'd be refered to someone else. He advised twice that a cause was unlikely to be found and wouldn't really make a difference anyway. (We didn't ask him about this at all.) All he was able to confirm that she was deaf (we knew this - she was fitted with hearing aids 3 months ago.) For us - this much anticipated appointment involved a 6am start and a six hour round trip to the hospital. We were asked only a few baisic questions which, if he'd checked his notes, he would have seen we have already answered. He had a quick look in her 'completely normal' ears. That was it. Such a disapointment after recieving such excellent care from the audiology team. Why were we given this appointment in the first place? And how long will it be before my daughter is actually seen by someone who's interested in her

Would recommend? (Friends and family test): Don't know

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 21/06/2018

hearing loss. This appointment that we were made to wait so long for seemed utterly futile.

Dear ELHell,

I have passed this to our ENT Clinical Director and he is happy to look into this for you. if you would like us to do this, can you please email me on [Eunice.goodwin@aapct.scot.nhs.uk] (mailto:Eunice.goodwin@aapct.scot.nhs.uk) or call me next week on 01563 826222 as I will be back in the office on Monday.

I am sorry you have found the service to be so disappointing.

Thank you for taking time to share this, feedback is important to enable us to make things better.

Best wishes,

**Eunice** 

#### **ELHell**

Thank you for replying quickly. I've emailed you.

We are preparing to make a change



#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 25/06/2018

Dear ELHell,

Thank you for contacting me off-line, as you know I have passed on the details as promised.

best wishes,

Eunice

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 24/07/2018

Dear ELHell,

You were expecting that your child would be seen at a Paediatric Hearing Assessment Clinic (PHAC), where the appointment slot is longer than a routine ENT clinic which is 10-15 minutes.

We are preparing to make a change

This (PHAC) clinic is run by a different specialist and is dedicated to investigation and management of children's hearing loss. These clinics are less frequent and have fewer available appointment slots.

Once this issue was identified, your consultant managed to rearrange your child's appointment slot with the colleague who runs the (PHAC) clinic, and we are delighted that you child's appointment is now in early August.

Once again may I thank you for contacting me. We understand more about the situation and it has flagged up an important area of which we are addressing. The manager tried to contact you yesterday to explain fully, she will try again today and I hope that your chat will help to alleviate any concerns or questions that remain.

I would also like to say that we are very sorry for not meeting your expectation at this appointment and for the distress caused. To prevent this happening again, we are looking for the best way to improve how we appoint children to the appropriate clinic.

As you know, the consultant would like to reassure you that the important management elements of your child's hearing loss is already in place.

Kindest regards,

Eunice



Maternity care 1 story

Food arrangements 584566

iif77 a carer 19/09/2018

I was staying with my partner after an emergency section and our daughter being put into intensive care.

719 views

My partner wanted me there as she was on crutches and sometimes in a wheelchair finding it difficult to get around and especially downstairs to feed the baby in intensive care.

I was glad at the opportunity to stay which was great however on the second day and not having eaten at all for a day and a half I went with my partner to where she got her food. A few things were available and she got her food.

I was then told I wasn't allowed any food to my slight surprise having never been in a position like this as I worked full time my whole life and provided for myself and my family.

I felt very uncomfortable and unwelcome despite actually staying full time in hospital to support my partner and with a new born in intensive care.

The only option for food then was a small coffee shop offering sandwiches and scones.

I am gluten free so found myself on two whole days without any food at all.

With my daughter in intensive care and my partner struggling this was really upsetting experience for me and again as I said made me feel like a beggar as well as very unwelcome.

**Attica Wheeler** Head of Midwifery (Associate Nurse Director Women and Childrens Services) NHS Ayrshire and Arran 19/09/2018

Dear jjf77

you raise a very good point of gluten free provision in our maternity café. I assure you we will address this today to ensure we have a range of items available for sale for partners and families remaining in the hospital with dietary needs.

I will also raise this with the staff that you should have been directed to our main restaurant in the linked crosshouse hospital that is used by staff and public alike. Here they have a wide range of food available all day.

I apologise that you were not made aware of this and this impacted as a negative experience for you whilst your partner was under our care. We do encourage partners to stay if they wish to for the holistic care and emotional well being of our women.

thanks for taking the time to share this with us

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 19/09/2018

Dear jjf77,

I am sorry you had such a difficult time and that gluten free food was not available in the café. Your post has certainly got things moving on this front. Today, there will be a discussion with the coffee place in AMU to ensure they have gluten free food and vegetarian food for partners. There will also be a leaflet for partners staying overnight, stating clearly where to obtain food and refreshments.

Well that is a great example of how the use of feedback, in this case Care Opinion, can initiate change so thank you for your post.

I hope all is well with you all,

Best wishes,

**Eunice** 

We are preparing to make a change



Neurology 1 story

# Life ruined by migraine

588965

chronicmigraine the patient 08/10/2018

324 views

My life has been ruined for the last 6 years by migraine which has gotten worse over time, I attend Neurology at Crosshouse Hospital in Ayrshire, I have tried oral medications but to no avail and most of them I have had to withdraw usage due to severe side effects. I attended an appointment some weeks ago at Crosshouse Hospital and my Neurologist explained that I am now onto the point that I require injectable treatments, the main one being Botulinum injections, the Neurologist explained that Crosshouse does not currently have a service for this and that they would have to write to the management of Neurology service at Crosshouse, I'm assuming to let them know there are patients that require this treatment. It has been 4/5 weeks and he has not had a response to this, this is incredibly distressing to me because I have chronic facial pain and severe migraines, I can have 15+ migraines per month, the fact that this amount of time has passed and no one from Neurology management at Crosshouse seems bothered that a patient/patients are living with a severely debilitating condition is really disappointing, I don't expect everyone to understand what this condition is like or the amount of pain and suffering that is endured. I am really in despair that just because of where I live and the apparent uninterest from Neurology management at Crosshouse, that I am now left in a period of limbo, not knowing where to go or what to do. I have stated that I do not mind travelling to Glasgow for this treatment or any other alternative hospital, I just want an appointment anywhere to have an opportunity to try and have any sort of life back that has been taken from me due to Chronic Migraine. I was told over the telephone that Glasgow hospitals were refusing Ayrshire patients, I don't know if this is the case but I desperately need some sort of resolution to this.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 17/10/2018



#### Dear chronicmigraine,

We are preparing to make a change

I have been asked to post this on behalf of David McCrone, Assistant General Manager, Medical Specialties, University Hospital Crosshouse.

"I am sorry that your migraines have progressed and I can only imagine how debilitating this must be and the impact this is having on your life.

I am also extremely sorry that you are unhappy with the management of this and you perceive that we have not taken any action to provide Botulinum (Botox) treatment for migraine in Ayrshire and Arran. I would like to take this opportunity to reassure you that this is not the case. I am delighted to say we are in the process of endeavouring to establish a service in Ayrshire and Arran.

\*\*Where we are at the moment\*\*

Before any new service is introduced, we need to ensure this service is the best course of action as a treatment; this has been done. A proposal to implement this has been discussed at our Governance groups both here and at UHA (Ayr hospital).

\*\*The next step\*\* is that we need agreement from our Pharmacy and the 'drugs and therapeutics committee'. Once agreement is reached, to ensure this is done safely, we then need to train the appropriate staff to carry out the procedure. Unfortunately as you can appreciate, this can all take some time.

I absolutely appreciate that this doesn't help you at this time, however, we have also been exploring ways that we can access this service in other health boards, as you suggested, in Glasgow.

I would like to reassure you that we are committed to implement this service. I am sorry that the length of time it takes to introduce a new service can be very frustrating, particularly when you are suffering so frequently with migraine. If you would like to contact me directly I would be happy to discuss the matter further.

My email address is David.McCrone@aapct.scot.nhs.uk and my phone number is 01563 826732.

Best wishes

David

Assistant General Manager, Medical Specialties

#### chronicmigraine

Unfortunately this does not help me at present as I am currently living in hell with frequent severe life altering migraines. Patients living with such severe pain and suffering should be sent to a hospital where it is available as a special rule, I do not find it humane at all that this treatment is 40 minutes away from where I live yet it feels like I live in a third world country, unable to access healthcare. My migraines have been severely life impacting, I do not have a life currently, my life revolves around chronic pain and sheer hell, I had to stop working due to this so I don't live a normal life during all these waiting times, I merely go round in circles in what seems like a constant battle to access the same health care others are receiving 40 minutes away from me., it simply is not fair.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 17/10/2018



#### Dear chronicmigraine,

I can only imagine how awful this must be for you and I am so sorry that we are not able to give you this service in Ayrshire and Arran right now. Can I encourage you to contact David McCrone by any chance? I am sure he will do anything that he can to help.

David's email address is David.McCrone@aapct.scot.nhs.uk and his phone number is 01563 826732.

I hope you get the treatment you need as soon as possible and you can start living again,

best wishes,

**Eunice** 

### **Respiratory medicine**

1 story

# We want proper care in our old age

542680

JohnnyK a relative 21/06/2018

In December 2017 my husband was called to Ayr Hospital for a scan following a bad chest infection. As he heard nothing he wrongly assumed that it was O.K. However, in mid January he was at Ayr Hospital for his routine bladder scope (he has bladder cancer) and a doctor looked at his notes and said he may have secondaries! Again nothing happened.

1,199 views

In February he had his birthday check with his G.P. I phoned Cathcart Street and spoke to Dr. McKenzie and said how worried I was about his scan. He then found that the scan in December had shown a shadow on his right lung, and was very worried that nothing had been done. Dr. McKenzie then organised an appointment at Crosshouse at the end of February. He confirmed that there was a shadow and he would need another scan and pulmonary function test. In April he has to go to 'on call' Dr at Ayr Hospital as he had a chest infection and feeling grim. Put on antibiotics.

We finally hear that my husband has to have a scan on towards the end of April at Ayr Hospital. We stupidly thought that this was for his chest but found out it was for the bladder area as Dr. Guran was wanting to check his pelvic area. When we phoned to see if this could have both areas scanned he was told this was not possible. However, a very sensible radiographer said there was no problem and did it.

We now move to May and I phone our surgery to ask why nothing is happening. They call us and get up the scan on the screen. The Doctor is very concerned and sends us to Ayr Hospital at noon. After 2 hours they start doing some tests, bloods, Xrays, etc. Our family arrive to give support. At 4.30pm a consultant doctor comes to hear our story and apologises. They have contacted urology and Crosshouse and say something should start to happen next week.

He gets a lung function test a week later at Ayr and a CAT scan at the Beatson at the end of May.

We return to see the Dr at Crosshouse in early June. As we enter the room the Doctor has not opened the file or put scan on the screen. After sometime they tell us the growth is bigger! They cannot find details of his pulmonary test and I tell them the date. Still can't find it. The doctor tells us that my husband will need a needle biopsy and depending on his fitness they could take part of the lung away. They said they will implement this and we should hear very soon.

In early June at Ayr my husband has an operation to look at his bladder, tube and kidney. The Doctor is optimistic that although in a mess it is not any worse. Bits taken for histology and my husband now bleeds and urinates every 20mins or less until mid June. Waterworks hasn't been right in 8 years but he copes and wears pads and rarely complains. Life is not easy but we accept our lot. I am just clear of breast cancer!

We both feel very alone and distressed that his condition has been left for all these months. He gets his results of urinary biopsy on July. This could have been at the end of June but we are having a holiday then and we've already cancelled one.

He has no complaints of Dr. Guran and the urinary department at Ayr. We are not looking for sympathy just proper care in our old age.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/06/2018



#### Dear JohnnyK,

We are preparing to make a change

Feedback is so important as it shines a spotlight on the things that go well and highlights things that have not. I agree entirely that you should get proper care as everyone should and I hesitate to say so, but I suspect these events are unrelated to age.

Our Assistant Director, John Swiatczak-Steele at Ayr Hospital, would like to look into this in order that we learn lessons from it. John will be very grateful if you would be kind enough to contact his office on 01292 614518, and give details such as your husband's name, address and date of birth.

Thank you so much for taking time to outline your husband's pathway and the failings within it. I am truly sorry that this has been both you and your husband's experience and we want to prevent it happening to others.

Kindest regards to you and your husband,

Funice

### John Swiatczak-Steele Assistant Director, University Hospital Ayr NHS Ayrshire and Arran 25/06/2018

Dear JohnnyK

Thank you for making contact with me today.

I have identified the appropriate manager to deal with your issue and I have asked that they contact you directly to ensure that we can resolve the outstanding concern we discussed this morning.

It has clearly been a distressing time for you and I can only apologise for the additional anxiety caused. It is extremely disappointing when things do not go to plan and I would like to understand and identify, as soon as possible, why this was the case for you so that I can ensure the correct systems and processes are in place to prevent from happening again.

Best wishes

John

John Swiatczak-Steele

Assistant Director of Acute Services, UHA

Stroke Care 3 stories

Nurses were great 517985

footballsq58 a service user 20/04/2018

Had a wonderful stay at ward 3E. Nurses were great. food good. only complaint (no shaving mirror).

All staff couldn't do enough for me

Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 24/04/2018

131 views



Dear footballsq58,

We have made a change

Being admitted to hospital is a real difficult time and it is great to hear your found your stay to be wonderful. The team will be delighted to read your feedback and I am glad you found the nurses and the food to be great!

As a team we recognise how stressful it can be and it is important that we support patients. I am glad you found all staff helpful.

Thanks for taking the time to provide your feedback. This is so important for us to review and develop our services. No matter how good the care is if we don't get it right with essential equipment then this can impact on your experience. From your feedback one of our nursing assistants Kevin has purchased 4 shaving mirrors for the ward. This will improve patient care moving forward. Thanks for highlighting this to

I hope you are now making good progress and best wishes for your future recovery.

Christine

### Noisy during the night

665767

matarzr98 a service user 12/06/2019

Referred by GP following suspected stroke.

277 views

Assessed at the CAU, University Hospital Crosshouse. Impressed by the curtesy and efficiency of staff.

Admitted to ward 3E where I continued to be impressed by the curtesy and efficiency of staff.

The ward was very noisy throughout the night so got little sleep. While a lot of this is unavoidable, due to it being a high dependency unit, some thought should be given to reducing the noise and disturbance during the night.

### Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 12/06/2019

Dear matarzr98,

Thanks very much for taking the time to post your feedback on care opinion. It is great to hear that you found staff to be efficient at all stages and respectful of your needs. The staff will be delighted to read this and I will ensure this is shared with them.

Coming in to hospital with a stroke is a frightening time and rest is so important as part of recovery. Although the ward is a high care area with monitors that alarm and a lot of activity there is no doubt we need to ensure that we reduce avoidable noise. You are right to highlight this and I will ensure as a team we look at ways to reduce noise overnight.

We are currently looking at getting an area within the unit where patients can be assessed for thrombolysis (clot buster) out with the 6 bedded area. We hope this would then reduce some of the noise. We very much appreciate your feedback and I will remind staff to minimise noise and look at any other ways to do this.

I hope you are now recovering well

Best wishes

Christine

Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 08/10/2019



Dear matarzr98,

We have made a change

Following your feedback we have piloted using ear plugs and eye masks for appropriate patients. This has proven very effective with patients describing them as a "godsend". Your feedback has been at the heart of the change and has already made a difference to a number of patients.

Within a high-care 24/7 receiving unit I can only imagine how noisy it must be and how this would have a negative impact on your experience. Through your sharing your experience on Care Opinion we have been able to enhance patient experience.

We now have ear plugs and eye masks available for all suitable patients.

Thank you,

Christine

# Attentive care and noisy nights

694692

188 views

limajw58 a service user 06/09/2019

I am most significantly impressed - positively - by the very short period of time I waited in A&E to be seen by a Dr via a triage nurse. Also rapid was specialised consultation and diagnosis and admission to hospital. Care is attentive and consultations with specialists are daily and open.

Staff on ward are helpful and involved.

I feel the period between 11pm and 7pm very difficult. Voices are, I believe, unnecessarily high, lights can be left on too long / late, perhaps the volume of clatter could be reduced - the above made sleep, even helpful rest, very difficult.

Overall I am deeply appreciative of excellent personal interaction and experience in Crosshouse Hospital.

# Christine Somerville Senior Charge Nurse NHS Ayrshire and Arran 09/09/2019

Dear limajw58,

We are preparing to make a change

Thank you for taking the time to post your feedback on care opinion. It is great to hear that you found the care from admission to discharge to have been excellent. The team will be delighted to read this.

I can only imagine how difficult it must be to try and get sleep in hospital. As the acute stroke unit is a high dependency area with admissions 24 hours a day it can be a noisy environment. I am sorry though your experience was much more than this. As a team we will take your feedback forward and will look at ways of reducing avoidable noise overnight and promote a more restful environment. There is no double sleep is important for recovery. If you have any other suggestions on how we can promote rest we would welcome your input. You can contact me via email: christine.somerville@aapct.scot.nhs.uk or 01563827933.

I hope you are now feeling better.

Best Wishes,

Christine

# **East Ayrshire Community Hospital**

1 story



### **Trauma & orthopaedics**

1 story

### Mum's potential cancer diagnosis

464225

Loving daughter 12 a relative 30/01/2018

329 views

In early November Mum had an appointment with her GP to get results of a recent MRI scan she had had done in relation to falls she had been having. The GP gave the shock news that the MRI had detected some 'suspicious looking leisons' in her spine and that the most likely outcome is that they are cancerous. She was given a CT scan which appeared to confirm these findings. She then waited until mid-December for a bone scan which has apparently given ambiguous results.

Mum has been passed from pillar to post and still does not know if the 3 highly suspicious leisons on her spine are indeed cancerous. To make matters worse still, it was suggested that they are secondary tumours from an undisclosed primary.

It will soon be 3 months since the initial 'diagnosis' and we are no further forward. We are all understandably very concerned about what is going on and I feel that she deserves to be treated in a far more cohesive manner in order to get to the bottom of what is going on and to offer her any possible treatment before things progress any further.

What can we do?

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 30/01/2018

Dear Loving daughter 12,

I am so sorry, this is such a horrible position for you and your mum to be facing and I do appreciate why you are concerned. Your Mum's experience to date does appear less cohesive than we all want it to be. I don't know what the situation is with your mum but we are very keen to find that out. With limited information it is impossible to guide you in the right direction, but if you contact me, I will see what I can do to help. My phone number is 01563 826222 and my email address is [eunice.goodwin@aapct.scot.nhs.uk](mailto:eunice.goodwin@aapct.scot.nhs.uk).

Thank you so much for raising this important issue. If you contact me, we can look into the 'process' of this. I am sure we can learn from this and help your mum too.

Kind regards,

**Eunice** 

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 01/02/2018

Dear Loving daughter 12,

Thank you so much for contacting me off-line. My heart goes out to you and your family, as I have said on this forum many times before, the unknown is so difficult to handle.

We are preparing to make a change

You consultant is committed to taking all the necessary steps to reach the fastest conclusion for your mum.

I suspect this may be of little solace for you both at this moment in time, but we will be reviewing the process your mum has gone through with a view to learning the lessons and improving the pathway for those to come.

Again, thank you for shining a light on this really important issue and again, may I say how sorry I am that you are still less clear about your mum's diagnosis but I trust it will be in the very near future. if there is anything further I can help with, please feel free to contact me.

With kindest wishes,

**Eunice** 



# **General practices in Ayrshire & Arran**

4 stories

### We want proper care in our old age

542680

JohnnyK a relative 21/06/2018

In December 2017 my husband was called to Ayr Hospital for a scan following a bad chest infection. As he heard nothing he wrongly assumed that it was O.K. However, in mid January he was at Ayr Hospital for his routine bladder scope (he has bladder cancer) and a doctor looked at his notes and said he may have secondaries! Again nothing happened.

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Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 22/06/2018



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Feedback is so important as it shines a spotlight on the things that go well and highlights things that have not. I agree entirely that you should get proper care as everyone should and I hesitate to say so, but I suspect these events are unrelated to age.

Our Assistant Director, John Swiatczak-Steele at Ayr Hospital, would like to look into this in order that we learn lessons from it. John will be very grateful if you would be kind enough to contact his office on 01292 614518, and give details such as your husband's name, address and date of birth.

Thank you so much for taking time to outline your husband's pathway and the failings within it. I am truly sorry that this has been both you and your husband's experience and we want to prevent it happening to others.

Kindest regards to you and your husband,

Funice

### John Swiatczak-Steele Assistant Director, University Hospital Ayr NHS Ayrshire and Arran 25/06/2018

Dear JohnnyK

Thank you for making contact with me today.

I have identified the appropriate manager to deal with your issue and I have asked that they contact you directly to ensure that we can resolve the outstanding concern we discussed this morning.

It has clearly been a distressing time for you and I can only apologise for the additional anxiety caused. It is extremely disappointing when things do not go to plan and I would like to understand and identify, as soon as possible, why this was the case for you so that I can ensure the correct systems and processes are in place to prevent from happening again.

Best wishes

John

John Swiatczak-Steele

Assistant Director of Acute Services, UHA

# Trying to get through via telephone.

enigma1966 the patient 11/12/2018

I'm certain that this is a common complaint. I called 25 times to order a prescription. I finally got through at 15.58 to receive a automated reply that all p/script calls had to be between 2-4pm. I have a few new prescriptions that are not on repeat, so I have to call. I depend on my meds to keep me stable.

I can't fault my local health practice as they are wonderful and always helpful:) But I can't help wondering why this the case. The receptionists are up to their eyeballs in calls and patients, why isn't there an application that patients can use?

With technology nowadays, there is an easy solution to calling...and I am aware of confidentiality etc etc. Surely regular patients should have the option of emailing their scripts?

Galston medical practice have always been wonderful - I actually pity the receptionists! They are in the firing line of a battle they can't win.

Would recommend? (Friends and family test): Extremely likely

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/12/2018

607706

233 views



Dear enigma1966,

We have made a change

I have been asked to post this on behalf of the practice manager, Shelley. This sounds as if it will be incredibly helpful. Do feel free to come back on to Care Opinion to let us know how it is working (after it is all up and running and any teething problems resolved).

"I am so sorry you have had trouble contacting us. We are very much aware of the issue for ordering prescriptions. Our plans to tackle this are to implement a prescription answering machine that will make telephone ordering available from 8:30am – 5:30pm. In addition to this we plan to implement online prescriptions to enable patients to order 24/7.

After a long battle with our telephone provider which started in August, and and with support from the Ombudsman, we managed to get released from our contract. We have finally had a new telephone system installed on Wednesday of last week. By way of explanation, the installation was not straightforward and today is the first day that we have not had engineers working on it. Unfortunately, there remains some work before it is completed and this has meant that our plans to implement the answering machine have had to be put on hold until we get the rest of the system working. We are optimistic that this will be set up within the next couple of weeks.

We are planning to go live with online prescriptions as soon as possible and we have the staff training sessions planned. Delivering training and keeping reception manned clearly relies on capacity. In order to fulfil the needs of the service moving forward, we have had 4 new recruits in the last 3 months. After these challenges, which may still be evident to some extent over the festive season. I would ask for your patience for a little longer while we iron this all out and I can r![Image title] (https://www.careopinion.org.uk/resources/posting-

images/responses/43f9d8e0d9d7441d904ab0066dcd7e73.jpg)eassure you that online prescriptions will be top of our priority list for the new year.

I hope this helps to update you on the current situation and you are reassured that we are doing the best we can to address them.

Thank you for taking time to share this feedback with us. Both positive and less positive feedback is invaluable to us. I have passed your positive feedback to the team; it is very much appreciated.

If you require any further information, please do not hesitate to contact me at the practice.

Kind regards

Shelley

Practice Manager, Galston Medical Practice

#### enigma1966

Thank you Eunice/Shelley for your positive, helpful response. This demonstrates that you are listening and acting upon patients comments. I look forward to the new system being implemented.



# Attending with chest pain and breathlessness

Heart strings the patient 20/02/2019

In mid February 2019 I took unwell at work with sudden onset moderate central chest pain radiating to my jaw with difficulty breathing lasting 5 min each episode. My symptoms eased after the second episode , which I then decided that instead of calling an ambulance, I felt well enough to attend my Drs surgery. I drove myself to the surgery and asked the receptionist that was on duty if I could see a Doctor. During this time I started to feel mild pain in my chest and jaw again which then disappeared .

I was informed by the receptionist that there were no doctors available at this time, as they were at lunch. I insisted to be assessed by someone because of the chest pain and feeling unwell and anxious. The receptionist was getting a bit irritated with me, and said they could do nothing for me, so went through the back and brought a laminate sheet to me with symptoms written on it. They said if I currently have any of some specific symptoms I should call 999. This receptionist left it up to me to decide if it was urgent enough or go up to the hospital, said its up to you? and carried on with accepting a parcel delivery. I was not invited to sit down in waiting room or have a glass of water offered to me. Not even an assessment by a nurseI felt distressed and confused as to what to do and also what was making me feel like this. So I left, possibly not well enough to make a rational decision at this stage. Angry and distressed that I couldn't find medical help at a GP surgery . So I drove to A and E and the minute I spoke to reception and nurse I was rushed through to resus. I had a STEMI and was in VF. I am now starting my recovery after this MI and stent insertion . At the time , a heart attack never crossed my mind as I'm only 48 yrs old and lead a healthy lifestyle. More likely my first panic attack, which wouldn't warrant a 999 call. 5 days on I still have distress about my experience at this practice. I feel let down by the practice that no healthcare professional was available to even do a quick assessment of my recent and ongoing symptoms and advise accordingly. There was no caring attitude towards my distress or support offered. I felt I was a nuisance. In hindsight I should have called an ambulance at work ,but I realise now I was not in the right state of mind at the time to make a rational decision.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 20/02/2019

Dear Heart strings,

I am saddened to hear that this was your experience at a time such as this. I am sorry you did not get the help you clearly required. Thank you for raising this with us, I think this has exposed an educational need. I think it was reasonable to expect more support and help from the GP practice. On hind sight, yes the right thing to do would be a 999 call, but I appreciate you were playing it down. Many people would have too, probably me included.

We would like to follow this up to make sure it does not happen again. Can you please call Neil Mellon, Primary Care Manager for Quality and Development on 01292 513843?

I hope you are well on the way to a full recovery.

Best wishes,

Eunice

630401

170 views

We are preparing to make a change



#### **The Cathcart Street Medical Practice**

1 story

# Grandmother with reduced mobility

457239

concernedforlongtermwellbeing a relative 15/01/2018

201 views

Contact has been made numerous times in the past 6 weeks to the appropriate district nurse team, regarding a much needed preventative measure for my grandmother who now has reduced mobility due to her condition and has become more or less bed ridden.

Depending on her daily wellbeing and health my grandmother is now only able to be out of bed some days for up to 5-6 hours. The much needed airwave mattress to help prevent pressure sores I was told this afternoon, via an answering machine message, was that my grandmother does not meet the criteria so will not be provided an airwave mattress.

I feel that this is unfair and unacceptable as some days now my grandmother is unable to get out of bed and we fear for her skin integrity, she is unable to move around whilst in bed to alleviate pressure upon her bottom and sides, please advise.

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 17/01/2018

Dear concernedforlongtermwellbeing,

I appreciate why you are concerned. It is difficult to be sure everything is as good as it can be when we are worried about someone at home that are less mobile. We want your gran to be protected too. I have spoken to the senior nurse for community in South Ayrshire and she will be happy to look into this for you. If you would you like to contact me I can arrange that for you. My contact details are phone - 01563 826222 and my email address is [eunice.goodwin@aapct.scot.nhs.uk] (mailto:eunice.goodwin@aapct.scot.nhs.uk). Thank you for raising this with us and giving us a chance to help.

Best wishes,

Eunice

### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 23/01/2018

Dear concernedforlongtermwellbeing,

We have made a change

Thank you so much for contacting me off-line. It is very heartening to hear that your gran now has the mattress. I am sure it will help. Once again, thank you for contacting us on Care Opinion and giving us the chance to help.

Best wishes,

Eunice

#### **Three Towns Resource Centre**

1 story

#### **General Psychiatry**

1 story

### Misdiagnosis & ASD Awareness

551035

Calypso a service user 09/07/2018

It took over a year and a lot of discussion to decide if I should write my feedback, but I feel it is now the right time.

misunderstandings, and I write things down when I need to.

1,836 views

I was diagnosed with an autism spectrum condition last year as a female adult in my 30s. This was done after almost two years of weekly private therapy exploring my difficulties with life and an assessment with a panel of national autism experts, who also interviewed my family and looked at my childhood, but which was at a huge financial cost. The therapy alone helped me feel supported and heard which saved my life when I had nowhere else to go - and adjustments were made to assist with communication and

Although I was diagnosed with depression and anxiety with social phobia many years ago and I agreed with

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this (and still do), an underlying picture was missed with the CMHT which led to a huge amount of misunderstanding, unhelpful advice and increased pressure to engage in activities that were beyond my capacity.

My psychological state continued to deteriorate. I was already struggling to manage day to day life as an adult trying to live independently with undiagnosed developmental condition. I asked for help and I wanted to overcome my difficulties, but various things were said to me which seemed judgemental and often dismissive, which is unhelpful to someone in the depths of depression. I was even told that I didn't have much stress in my life by a nurse who barely new me, but I didn't have the understanding or words to say exactly how wrong she was.

Although, this wasn't always the case, some showed more understanding than others, including a time when a male nurse took the crisis risk issues seriously and sent me for a hospital admission which I attended, but then it was agreed with the duty doctor to try some intensive help from the crisis team instead, which turned out to be less than helpful as they had a familiar attitude towards me and I ended up back where I started.

I am now aware my communication difficulties complicated the misunderstandings, but I am also not as frustrated as I once was. Although I think labels can be very unhelpful and stigmatising, I needed to know and people in my life needed to know why I experienced the world the way I did, as previous attempts to understand myself didn't make much sense in the end, including why I spent much of my school and college life perpetually confused, exhausted and unable to speak, or why I wasn't interested in the usual teenager things, despite being well behaved to the point I'd be distraught if I inadvertently broke rules.

The diagnostic report said it hopes it will provide closure and was help me to develop better coping mechanisms and receive appropriate support. I am more hopeful that it will once I am able to process more of what it all means for my life. I am already making grains in that area, as I am now able to communicate when I am overwhelmed or frustrated and why (e.g. being flooded with information I can't process or struggling with communication issues, sensory, etc). My relationships are closer too. My GP now allows for extra appointment time to take pressure off me, which I am thankful for. Little adjustments make a big difference when dealing with people

Autism awareness needs to improve in the services. No one correctly picked up what was going on for me. My second and final request to find suitable doctor to look at my case was dismissed as an interpersonal problem in the end, when I had valid reasons for doing so – although perhaps I did not communicate those well enough. I hope the renewed (2016) SIGN guidance for referrals for diagnostic assessment for adults with ASD will improve things. I knew something was missing with my case because the CMHT's understanding of me was so far off. Other people in my life agreed with this but they were not listened to either.

I don't believe most of the problems I encountered were particularly personal. I understand services are stretched, but I can't help but feel failed by a system that was meant to help. Other issues were also missed, including obsessive/compulsive issues which worsened after my overdose in 2015 after difficulty coping with my hospital recovery concerning brain injury, and sudden change of environments again (which I struggle with). Since then I was left without any NHS mental health care and then discharged without being informed or having my new medication reviewed. If I did not have the funds to seek private support, I would not be here today.

Finally, I must also be clear that rushing someone to give answers to questions is unhelpful, such as saying "it is a yes or no answer", or "it is a simple question" while I am trying to process the question and form/organise my thoughts and then answer. I would often rush answers because I wanted to be compliant, but that was at the expense of accuracy. Although, I understand it was not known I was autistic and may have required more time than other people to aid communication.

Would recommend? (Friends and family test): Neither likely nor unlikely

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 11/07/2018



#### Dear Calypso,

I read your post closely and I find it very difficult to imagine how awful this must have been; from your early years through to your eventual diagnosis. I think you have shown that we have a long way to go to learn how distressing even a 'simple' question with a 'yes/no' answer can be for some.

I personally feel humbled. I am sure to have had contact with people with autism spectrum condition throughout my career and I can hold my hands up to say that I did not understand as well as I do now (with your help).

I think your points are well made and I intend to share your post internally and externally so we can benefit from the insight you have given us.

I thank you so much for taking time to give us such a full explanation and providing us with a better understanding of your plight in reaching a diagnosis. I would also like to apologise on behalf of all of us for not fully appreciating or understanding and for how long it took to reach your diagnosis.

Best wishes,

Eunice

#### Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 11/07/2018

Dear Calypso,

I passed your post on to the community mental health team and learning disability team (amongst others). The Community MH team have discussed this and have taken this on board for learning and improvement in the team. They are aware they can do things better (can't we all). While this will not happen over night, it is on their radar.

I have also shared your post via FB and Twitter. (You may see a blue moon tonight, I don't tweet often).

Thank you for putting these issue in the spotlight.

best wishes,

**Eunice** 

Calypso

We are preparing to make a change



Thank you, Eunice – that is much appreciated.

Apologies for the length of my post. I couldn't trim it down as much as I had hoped but I wanted to highlight the key points with examples that could be helpful, rather than just moan about the situation. I wrote many drafts over the year and had to finally decide to "let go" to put my experiences behind me.

It is good to hear that changes are on their radar and it is understandable any real change will take time, but any move in the right direction is good.

I was quite afraid to post my experiences because past attempts to fight my case didn't end well for me and just increased the sense of mistrust and confusion I had increasingly felt. A lot of mental gridlock and lack of hope!

But this is an issue I feel strongly about, and I am deeply concerned about the situation on a national level too concerning late diagnosis, lack of specialist adult autism services/training and the damage it can cause.

We're already have significantly higher risk of co-occurring mental health problems, such as chronic depression/anxiety disorders, self-harm and suicide. It is so important that NHS staff are better trained to recognise those who may have become lost in the system, or what adjustments are needed. I am far from being alone with my experiences.

Also, if nothing else, sometimes just carefully and patiently listening and allowing people to release the brain-pressure can help meet a need for someone struggling with life and a lack of options/hope. I know it would have for me. I feel awareness of that basic need can get lost somewhere within services.

Eunice Goodwin Patient Feedback Manager for NHS Ayrshire and Arran NHS Ayrshire and Arran 12/07/2018



### Dear Calypso,

Again, you raise your points so eloquently and in a very balanced way. I think the problems you have faced will certainly resonate with others and it was both brave and clever raising this via Care Opinion. I hear how strongly you feel and I wonder if linking with some of the charities that work on behalf of Autism could help strengthen your voice. I have pasted (below) some contact details for the National Autistic Society.

You are probably aware of this charity, but perhaps it would be worth joining them to help improve awareness, diagnosis and treatment.

I will ask our communications team to tweet this message and Care Opinion planned to tweet your post too.

Twitter: @autism Facebook: National Autistic SocietyMain contacts

Email: nas@nas.org.uk

Autism Helpline: 0808 800 4104

Supporter Care: 0808 800 1050

Training, Consultancy and Conference: 0141 285 7117

Head Office Switchboard (administrative enquiries only): 020 7833 2299

Keep your passion and keep pushing, it is with people like yourself that makes change happen.

Best wishes,

Eunice