**East Sussex Wheelchair users and their carers**

**Experiences of using emergency ambulances provided by South East Coast Ambulance Service (SECAmb) in East Sussex**

**REPORT**

The project brief was to capture some feedback from East Sussex wheelchair users and carers’ experiences of accessing 999 ambulance services provided by South East Coast Ambulance Service (SECAmb). This arose from concerns shared with the East Sussex Wheelchair Service User group from wheelchair users and their carers. The issues raised related to problems with transporting wheelchairs in ambulances and concerns about safety for moving and handling people living with postural and complex medical conditions. There are approximately 15,000 NHS wheelchair users living in East Sussex alone. Around 10% of these NHS wheelchair users are aged under 18. Some young people have specialized, powered, privately provided wheelchairs. Young people and adults are issued with bespoke powered wheelchairs on the NHS to meet their prescribed clinical needs.

**Survey responses**

A survey was circulated for wheelchair users and carers to complete prior to the live feedback meeting which took place in Eastbourne with senior staff from SECAmb, wheelchair users, parents and carers on 21 September 2018.

There were 12 responses to the survey. 2 surveys returned by parents whose children use bespoke powered wheelchairs. 10 were completed by adults, 5 adults aged over 65 and 5 adults aged under 65. Of the adults 7 are powered wheelchair users and 3 use manual wheelchairs.

*The detailed responses to the survey are in Appendix 1.*

*The survey questionnaire is in Appendix 2.*

**Live feedback meeting (21 September 2018)**

The meeting was attended by 9 adult wheelchair service users, 2 adult carers, 1 Senior paediatric nurse and 1 Care Manager from Demelza Hospice Care for Children in East Sussex; 4 parents and 1 child. SECAmb was represented by John Griffiths, Head of Fleet and Logistics and Nicola Brooks, Head of Effectiveness and Experience. Lorraine McDonald from Healthwatch East Sussex joined the meeting at the start to explain the support Healthwatch can offer to service users and carers, including information about advocacy provided by South East Advocacy Projects (SEAP).

**Key issues from the survey responses and feedback meeting**

* Most children and adults with complex postural and medical needs cannot transfer from their wheelchairs onto a stretcher, so they would need to go to hospital in their own bespoke wheelchairs wherever possible and where it is safe to do so.
* Children with palliative care needs and complex conditions often have Oxygen and feeding systems attached to their wheelchairs.
* Parents shared their experiences of the difficulties of getting their children’s wheelchairs to hospital, sometimes having to take them on the train (example given in the meeting of a child being taken to a London hospital). Bariatric ambulances have to be sent from out of area to take a child to London as standard ambulances cannot accommodate the equipment, plus the patient in their wheelchair and their carer(s). This has also been the experience of some adults where they needed to be taken to London and there were delays as the bariatric ambulance provision is very limited. Although it was noted that the standard ambulance stretchers can accommodate weights up to 40 stone, sometimes the patient’s other needs including their postural needs/shape will necessitate another vehicle to be provided.
* Patients with complex needs who use wheelchairs often do not have up to date information recorded on the SECAmb system when they make a 999 call. Updating the patient record in each case is needed. However, SECAmb would not delay dispatch of a paramedic in an emergency, as meeting the emergency needs of the patient always takes priority over any other practical considerations. A parent shared their experience of a life threatening situation for their child and if there is any further delay in getting paramedics dispatched on any future occasion, the delay might be even more life threatening. The “*worst situation to be in as a parent of a child with a serious condition is where a 999 call does not result in a fast response to get there in time”.*
* Some patients have a Patient Specific Instruction (PSI) [[1]](#footnote-1) to hand to the paramedics. This is a practice currently **not** used by all parents or adults. The SECAmb IBIS (Intelligence Based Information System) record is a patient care record completed by the patient’s main healthcare professional and shared via SECAmb’s electronic IBIS system. These are linked to the patient’s address, however if the patient is staying elsewhere (such as in a hospice) the record would not automatically show up on SECAmb’s computer-aided dispatch (CAD) system. It was noted though that TWO addresses can be accommodated on the patient record, to also include the child’s school or adult or child’s hospice/respite care address for example.
* Patients who are in emergency situations in the community take priority over patients waiting for urgent transfer in hospital, but only if the assessed category of the emergency/clinical need of the patient waiting in the community is more urgent. Therefore, patients who are waiting in hospital for emergency transfer to another NHS service or hospital will take priority if their assessed need is more urgent. It was acknowledged though that delays to transfer cause frustration and distress particularly for parents and their children waiting to be transferred from a local hospital to out of area, to London for example in order to receive urgent, ongoing treatment.
* There is a standard set of medications that SECAmb paramedics are authorized to give, and it was noted that with both children and adults, where they have specialist medication prescribed the paramedic might not be authorized to administer the medication in an emergency situation. The Patient specific instruction (PSI) needs to be updated to list any specific, bespoke medication(s) **already prescribed** by the patient’s own primary health care practitioner or hospital consultant. In order to meet the medical needs of the child or adult, the patient or their carer needs to have this prescribed medication available to give to the paramedic to administer, but this must be detailed and specified in the individual patient’s PSI.
* It was unanimously agreed that whilst paramedic services are excellent and well respected, yet there remains a real need to listen more to the patient as being an ‘expert patient’ on their own needs. This is particularly crucial for patients with complex medical and postural needs. Parents are the experts in respect of their child’s needs and have insight and knowledge about the medication their child needs (to reduce fits for example) and must always be listened to, particularly in emergency situations. Both patients and their carers must always be listened to carefully by paramedic staff.
* New ambulances in East Sussex (although a longer wheel base and more height) have even more restricted space to accommodate a wheelchair. It was noted though that this is a national standard specification that has been introduced throughout the UK.
* It was a common experience for adults and children to arrive at A and E without their wheelchair or essential mobility equipment. This causes extreme anxiety and is also unsafe for most patients with complex needs who are entirely dependent on a bespoke wheelchair that is customized to their specific clinical needs.
* For patients with complex postural issues, being moved into a prone or semi prone position onto a bed or stretcher can potentially be life threatening. This can apply where the person is in respiratory failure, or where they have conditions that can be made worse by being moved out from a seated position in their own wheelchair and onto a stretcher or hospital bed. Patients should always be listened to and staff respond carefully to their individual requirements for being moved, taking account of their postural shape and any risk(s) posed to their health, as well as their safety. All needs should be included in the individual’s IBIS record or PSI.
* There were problems described in the meeting with hospital discharge and struggles getting home without the patient’s own bespoke wheelchair being available to them to support them to return home. It was noted though that this is not the responsibility of SECAmb. This is the responsibility of the Hospital Trust treating the patient, or the Non-Emergency Patient Transport service (PTS) who will need to make arrangements to safely transport the patient back to their home upon discharge.

**RECOMMENDATIONS/ACTIONS TO TAKE FORWARD**

1. Report back patient experiences to the national ambulance fleet group and identify any technical solutions that might reduce the negative impact upon patients who are wheelchair dependent, including any practical adjustments to the existing ambulance fleet. **ACTION: SECAmb Head of Fleet and Logistics**
2. Investigate the National Design standard for emergency ambulances and the impact upon patients who are dependent on their wheelchairs for being transported to A and E departments. **ACTION: SECAmb Head of Fleet and Logistics**
3. Create/update all IBIS records/ PSIs for those who took part in the project, where appropriate, including information in each case about postural needs and wheelchair dependence. IBIS records/PSIs can be completed/updated for the 999 service, as well as the 111 (out of hours) service. The IBIS records will provide information to assist with transfer at A and E, ensuring postural needs are taken account of when the patient is moved onto a hospital bed or trolley. This detailed record should also include information about any hospital where the child or adult is being treated on an ongoing basis and where their medical notes are held. Transfer to that location might be in their best interests if they are stable enough to be transported. **ACTION: Individual patients to initiate with their primary health care practitioner/hospital consultant**
4. Ensure, where PSIs and IBIS records have been created or updated for individual patients, that any specialized medications prescribed by their primary health care practitioner or hospital consultant are held by the patient or their parent/carer for administering by the paramedics. This should be as specified in the PSI for that patient. PSIs could also include information about any Advance Decision prepared by the patient and lodged with their GP, as well as any Do Not Resuscitate instruction (DNR) that the patient wishes to be upheld and has confirmed in writing in advance. **ACTION: Individual patients to initiate with their primary health care practitioner/hospital consultant**
5. Explore in conjunction with the NHS wheelchair service about putting in place contingency for local mobility private suppliers to pick up a patient’s wheelchair and transport it to them in A and E. This is particularly crucial where the NHS wheelchair has been abandoned in a public place or where the patient has no means of getting the wheelchair transported themselves. Patients also need to be aware of how they can put in place their own contingency plan(s) for their own wheelchair/equipment and ensure this is specified on their PSI/SECAmb Patient record. **ACTION: Wheelchair users/carers/with advice from NHS wheelchair service**
6. Liaise with partner organizations to communicate information about the 111 service and its open access to patients needing support rather than calling 999 and needing to go to hospital (unless it is an emergency that warrants hospital admission). Also communicate information to patients and carers about the Crisis Response Teams (access via a GP) who can provide emergency support at home for short periods to treat acute illness in some cases, thereby avoiding admission to hospital. **ACTION: East Sussex Wheelchair group, liaising with organizations supporting service users and carers**
7. Share the project report with SECAmb’s Patient Experience Group and Inclusion Advisory Group. **ACTION: SECAmb Patient Experience Manager**
8. Liaise with Healthwatch East Sussex, Commissioners and Care Quality Commission to identify respectively: any further actions to take forward, impact upon commissioning and to report the project as a positive example of involving patients in their access to emergency ambulance services. **ACTION: East Sussex Wheelchair group**

*With our thanks to East Sussex wheelchair users, parents and carers who participated in the project, to East Sussex Parents and Carers Council, Healthwatch East Sussex, Possability People, and Independent Living East Sussex for their support*

*Our sincere thanks also to South East Coast Ambulance Service Patient Experience Team for their proactive co-operation in taking action to improve support for wheelchair users and carers in East Sussex*

**APPENDIX 1 SURVEY RESPONSES**

**Q3. In the event of an emergency could you or the person you care for be *safely* transferred out of the wheelchair into a different postural position and onto an emergency ambulance?**

**Please tell us more about any postural needs, and what would be the safest way for either you or the person you care for to be moved. Please describe any postural needs that would arise whilst accessing an emergency ambulance from home, and what would be needed if an emergency should arise away from home?**

‘In terms of safety I can be transferred out of my wheelchair in an emergency, but because of the different height between my wheelchair and any bed or ambulance stretcher this can be extremely difficult, painful and potentially dangerous. Any movement into a different postural position would have serious implications for my respiratory system. Paramedics need to listen carefully to what I need. Patient is often the expert, not anyone else. I cannot move without being re-positioned by my Personal Assistant who is with me all the time. Any bench bed or narrow stretcher will not accommodate my shape. Any movement into a prone or semi prone position can seriously compromise my breathing as I am in chronic respiratory failure. The safest postural position is for me to remain in a seated position. This is also due to my legs which I cannot move unaided’

‘Bariatric (large) ambulance needed to transfer my large powered wheelchair. Am weight bearing but only just and cannot stand or walk. I have a lever on my bed at home to get out of my wheelchair. Very difficult to transfer. Having my wheelchair is essential for me to transfer out of the wheelchair and onto a bed in hospital’

‘I need a postural/vacuum mattress or other suitable inflatable lifting device to move me safely from the floor. I have limited transfer (lateral) only ability to transfer myself from my wheelchair to a seated position at the same level. I cannot walk at all’.

**‘As a Thalidomide survivor; my shoulder joints have a tendency to partially dislocate & my hip joints are flexed. Being lifted, unless that is the only viable option in an emergency, is not really a ‘safe’ solution. Assuming I am conscious, transfer to a semi-prone (not flat) position with guidance from me is possible’**

‘Anything other than sitting in my wheelchair is very uncomfortable and causes much discomfort’

‘I have severe brittle bones and osteoarthritis, with nerve damage, also contractures in my joints from repeated fractures. I can only lie in a semi prone position and manual handling can result in spontaneous fractures’

**Q4. Do you or the person you care for have other essential medical or mobility aids, such as respiratory support equipment, transfer boards or communication aids?**

**‘Powered wheelchair, Transfer boards, NIPPY3 plus machine for respiratory support, Cough assist machine’**

‘Transfer board’

‘S**uction Machine’**

**‘Walking Stick with a special handle designed for Arthritic hands**

**Plus a Flexyfoot ferrell (fitted) for stability’**

**‘2 COMFORT GRIP WALKING STICKS WITH TRIPOD FERRULES’**

**‘Transfer board CPAP, suction unit, oxygen’**

**Q5.**

**If you or the person you care for needed an emergency ambulance to travel to Accident and Emergency (A and E) (or be transferred in an emergency between hospitals for essential treatment) could you or they manage without the wheelchair, as well as without any essential medical, mobility or communication aids?**

**‘Without my wheelchair I cannot sit safely, because of its bespoke design and seating system. This protects my posture and my breathing function. Without my NIPPY 3 plus machine my CO2 levels would rise and my oxygen would reduce to clinically unacceptable levels. Administering oxygen alone could be dangerous in my case and any regime must be combined with my NIPPY machine. Consultation with my clinical team for my respiratory condition is absolutely essential’.**

***‘I am a full time wheelchair user in a large powered wheelchair. I cannot transfer without great difficulty and it is essential that I have my power wheelchair with me on the wards and for transfer between hospitals’***

**‘My power wheelchair is essential for my individual needs, postural support and for safety of transfer between the wheelchair and a hospital bed for example’.**

‘I can't manage with at least walking aids for very short distances which decreases when unwell, therefore would require staff to assist to toilet and usually I have to explain why I need help every time as conditions are complex and although I can walk pain and fatigue are huge and balance poor this discourages movement which increases pain’.

**‘I cannot walk or stand at all, I would be unable to move/be moved unless on a stretcher/trolley; one of the porter’s wheeled chairs would be unsafe for me & cause considerable pain, regardless of whatever injury I was being treated for’.**

‘Anything other than sitting in my wheelchair is very uncomfortable’

**‘My severely disabled child is unable to sit or support their selves and needs specialist seating system’**

**‘I live life entirely in a wheelchair. I cannot walk and only stand briefly to transfer’**

**‘I would require my walking stick for balance’**

**‘Cannot sit without supportive seating and if have no wheelchair it would affect breathing and oxygen levels, also would cause a lot of pain’**

‘I need my bespoke powered wheelchair that has been prescribed for my specific clinical needs as without it I am at risk of severe pain, tissue/nerve damage and fractures’

**Q6**

**Please describe in more detail what happened on occasion(s) when you called for an Emergency ambulance (999 service) in East Sussex? Please tell us if there were any problems with transporting the wheelchair and any specialist aids or equipment either to A and E, or for other emergency transfers between hospitals?**

‘About 4 years ago I was hospitalized as an emergency due to what turned out to be acute sepsis infection. Whilst I was acutely ill with a high temperature and had rigors I found myself in an impossible situation as I could not take my wheelchair on board the ambulance. I was lucky that my PA on that occasion could transport my wheelchair and equipment to A and E.

If this had not been possible there would have been a very serious risk to my respiratory function and my overall postural needs. As it was I was left on a trolley for several hours which caused me extreme distress and pain. I was very traumatized by the whole experience. I was not listened to and I was treated as though all the medics and staff knew best about my condition’.

‘About 3 years ago I called 999, but I had great difficulty getting the call handler to understand I needed to be seen by a paramedic. It would help greatly if my needs had been understood and recorded accurately on the system. I thought my age was a barrier. Eventually the paramedics came and transferred me on an ambulance in my wheelchair to the Conquest Hospital, where I underwent emergency surgery. Paramedics were excellent’.

‘I had a serious fall in the shower in May 2018. I experienced a huge and very painful whole body spasm which caused the shower seat to tip forward and then I was dumped unceremoniously onto the bathroom floor. I have Multiple Sclerosis and standing is impossible. I had been advised previously that I should call 999 in an emergency which is what we did. After asking a few questions it was concluded that I was not an emergency and I would have to wait approximately 2 hours. I was not aware of any bleeding or pain at that time. This was at 6.30pm in the evening. After 2 hours of waiting I phoned 999 to ask what progress was being made to be told that I was low priority and the service was very busy. I was told to just wait, but I could hardly do anything else as I was still lying flat on the floor and I could not even sit up. My wife went to get some blankets and a duvet as I was wet and the concrete bathroom floor is very cold. I was getting colder and colder and still unable to move. Eventually at around 1 am we received a call to say that the paramedics were on their way. It was a further 15-20 minutes before a sole paramedic arrived. They only then realized it was a 2 person job, so an off duty friend living nearby was contacted by the paramedic who then came to assist. Between them I was lifted by means of an inflatable cube shaped device to the level of my wheelchair seat. I was then able to transfer onto my wheelchair and then onto my bed. I was embarrassed that after 6 hours I burst into tears due to being so cold and so very upset by being on the floor for so many hours. Following the emergency incident I have described I am very nervous about transferring from anywhere to anything. The stair lift in my house is a challenge and I pause before doing transfers. Transferring from my wheelchair to any other seat is something I avoided. The only transfer I could do with confidence was the transfer sideways onto my bed. I would not transfer onto the toilet without my riser/recliner, because that to me is a challenge I am not prepared to take. We understand that for non- emergency situations we should dial 111, but speaking to paramedics (who are wonderful people and who themselves are embarrassed by the time it takes to be able to respond) they insist 999 is the only way to get attention.

7 hours lying on a cold floor and wet at night gave me cause to think. As I get older and my condition causes me to be more prone to falling I wonder if the falls service as it exists in Eastbourne could be extended, when one considers the age of the population. The numbers of accidents that happen to older people could be prevented from being worse by the falls service getting people up more quickly, thus preventing more serious and unpleasant complications’.

‘On no occasion have I been allowed to take walking aids or wheelchair which made me dependent on overstretched staff for every movement out of bed’.

‘**In May 2014, I fell from my wheelchair into the road in Bexhill, the castor of the wheelchair caught in a pothole on a zebra crossing. My partner rang 999, it was clear I was in a lot of pain & could not be moved by non- professionals. A paramedic in a car, on a different shout, stopped & rang in that I was more urgent & to send an ambulance. He gave me morphine & assessed me. When the ambulance came, the transfer on to the stretcher from the road surface was difficult but they listened both to me & to my partner; I was NOT laid prone. The paramedic followed to the hospital to administer more morphine before I was unloaded as it was going to jolt me more & he thought I had broken bones, he was right. I was shocked that neither of the paramedic technicians on the ambulance were qualified to administer morphine?? At no point was my wheelchair mentioned & my partner put it into the car; looking back it was not even considered as important. It became clear at the hospital (Conquest) that my injuries, both legs were broken, would mean that I wouldn’t be using my wheelchair for a while and my partner then took it home. I was taken home by ambulance, PTS, on a stretcher, after considerable discussion as to the viability of their trolley going through our front door & maneuvering through the narrow hallway! Although I’ve said the wheelchair I use is not NHS, this from choice, I’m lucky that I can afford an Otto Bock one; I do have an NHS one as I am entirely reliant on a wheelchair for all mobility, both inside & out’.**

‘Luckily my husband has always been there with my wheelchair’.

‘I had to follow behind my child with the wheelchair in my vehicle, this has happened on several occasions’.

‘I had to be taken to A & E in my mobile chair I was not allowed to stay in my electric chair. When it was time to come home I had to arrange my own transport home in a taxi. Had I been in my electric chair I could have made my way home more easily as I had no helper with me’.

**‘My wheelchair has quick release wheels, but will not fold. My wheelchair is used in conjunction with a Batec (electric) [trade name] which is a power unit to for propelling the wheelchair. And converts any wheelchair into a Trike. I could not (cannot) propel the wheelchair manually’.**

**‘My powered wheelchair will not fit into an ambulance so it needs to be transported later on’.**

‘Having no wheelchair has delayed discharge, caused a lot of pain and needing further medication. A transfer from Brighton to a London hospital I could travel with my child as the ambulance could not take the wheelchair, so I had go with the chair via train, which was distressing for my child and me’.

**ANY FURTHER COMMENTS**

**‘From what I have seen & heard, training of staff to understand the vital importance of wheelchairs & other vital equipment to the lives of disabled people is paramount & needs to be delivered, at least in part, by disabled people ourselves’.**

‘Improve the experience of some wheelchair users using emergency ambulances; where appropriate allow a patient to remain in their own wheelchair’.

**APPENDIX 2 SURVEY QUESTIONS**

**GAPS AND BARRIERS: KEY QUESTIONS FOR WHEELCHAIR USERS AND THEIR CARERS IN EAST SUSSEX**

1. **Are you a:**

A. **Wheelchair user**? YES\* **(**\****please delete answers as appropriate)***

B. **Parent or Carer of a child or young wheelchair user aged *under* 18?**

C. **Parent or Carer of a wheelchair user aged *over* 18?**

D. **What is your age group or the age group of the person you care for?**

Under 18/18-25/25-50/50-65/over 65

1. **Has the wheelchair been provided by the NHS?**  YES/NO

 **What type of wheelchair is it?**

A. Powered wheelchair Manual wheelchair

B. **Please describe the approximate size and weight of the wheelchair?**

Approx size: Approx weight:

1. **In the event of an emergency could you or the person you care for be *safely* transferred out of the wheelchair into a different postural position and onto an emergency ambulance?** YES/NO

**If NO, please tell us more about any postural needs, and what would be the safest way for either you or the person you care for to be moved. Please describe any postural needs that would arise whilst accessing an emergency ambulance from home, and what would be needed if an emergency should arise away from home?**

1. **Do you or the person you care for have other essential medical or mobility aids, such as respiratory support equipment, transfer boards or communication aids?**

YES/NO

**If YES, please describe them**

1. **If you or the person you care for needed an emergency ambulance to travel to Accident and Emergency (A and E) (or be transferred in an emergency between hospitals for essential treatment) could you or they manage without the wheelchair, as well as without any essential medical, mobility or communication aids?**

YES/NO

**If NO, please tell us why:**

1. **Please describe in more detail what happened on occasion(s) when you or the person you care for called for an Emergency ambulance (999 service) in East Sussex? Please tell us if there were any problems with transporting the wheelchair and any specialist aids or equipment either to A and E, or for other emergency transfers between hospitals?**

**ANY FURTHER COMMENTS:**

1. A Patient Specific Instruction or PSI is essential when a paramedic is required to provide care or treatment that is outside of their scope of practice, e.g. to administer a drug they would not normally be authorized to give. PSIs are created in collaboration with the patient’s GP or specialist health professional, and it is then signed off by one of SECAmb’s consultant paramedics or medical director. [↑](#footnote-ref-1)