

PACE SETTER Award goes to Worthing GP surgery for its care of young patients with additional needs

To a child with a disability or an additional need such as autism or a learning disability, the commonplace event of going to see the doctor can be confusing, upsetting, over-stimulating or even frightening. As well as causing obvious distress to the young person, these reactions often present a considerable challenge to the parent carers accompanying them - and sometimes to GPs and other practice staff too.

St Lawrence Surgery in Worthing has worked hard to improve the experience for their young patients with special needs and/or disabilities (SEND) or life-limiting conditions. The excellent support offered by the surgery has won them their first ever PACE SETTER Award - an NHS-sponsored initiative to celebrate, reward and promote high quality practice for children and young peoples' services.

Challenges for parent carers and the GP surgery

“Two parent carers in particular were telling us about the difficulties they faced when bringing their youngsters to the surgery,” says Debbie Elcome, St Lawrence Surgery’s Practice Care Coordinator. “We soon realised other parent carers had similar problems and that our practice hadn’t connected with our group of young patients with additional needs quite as well as we had with other vulnerable patients such as older people.”

The wide spectrum of diagnosed disabilities represented among this group of 114 patients under the age of 16 included neurological special needs such as autism, ADHD and learning disability, plus physical disabilities like spinal changes and visual impairments. There are 14,000 registered patients at this surgery. It was difficult knowing where to start to make meaningful changes for all their young patients but the PACE SETTER Award gave a clear framework.

The PACE SETTER Award UK

PACE SETTER Award encourages the development of NHS teams and organisations that provide high quality services to children, young people and their families/carers, are attuned to the needs of the local population, supported by their CCG and

provider Trusts, and celebrated by both their service users and the whole team caring for them.

PACE SETTER is

- endorsed by the Royal College of General Practitioners (RCGP)
- approved by Healthwatch West Sussex
- approved by the Royal College of Paediatrics & Child Health (RCPCH)
- sponsored by the NHS South East Coast Strategic Clinical Network (SEC SCN).

The clear structured guidance set out in the award: **Apply; Agree; Act** and **Achieve** sets a clear framework to work towards and measure impact resulting in an accredited Award. To register go to <http://www.coastalwestsussexccg.nhs.uk/pace-setter-award>.

See PACE SETTER Award for guidance -

http://www.secscn.nhs.uk/index.php/download_file/view/373/738.

Parent enrolment & taking stock

The initial step towards their PACE SETTER Award was for GP surgery staff to consult with and enrol key parent carers to their 'working party'. Parents Lindsey Butterfield and Zoe Green had previously approached the practice about their children's challenges and are linked to the local Parent Carer Forum and National Autistic Society groups. The working party invited all parent carers of young patients with additional needs to a friendly meeting to discuss precisely what wasn't working for families and what could help. Contrary to expectation, parents spoke openly about numerous difficulties such as struggling to get their child from the car to the surgery due to severe anxiety about doctors' appointments; the waiting room being too noisy and not child-friendly; being judged by other patients when their child's behaviour drew attention to them; and having to explain their son or daughter's condition to the receptionist and GP at each phone call or appointment. Seeing a different doctor was also a problem for some young patients whose additional needs cause them distress at unexpected changes.

Immediate changes and new initiatives

An important new initiative is the introduction of '**My Medical Passport**'. This is completed by the parent or young person themselves and gives essential information to help clinicians and practice staff get the best from consultations. It lists the young person's usual behaviours, ways to communicate, things that may upset them, and how to calm them as well as contact details, diagnosis and whether or not the young person knows their diagnosis. The Passport is linked to medical

records so that, no matter which GP or nurse they see, staff can instantly view the vital information.

Enhanced patient 'flagging' helps when parents phone the surgery, if there is a diagnosis of a disability or life-limiting condition, this pops up on staff screens immediately, alerting receptionists to tailor their advice accordingly, being aware, for example, that having to wait a long time for an appointment may cause more stress than for a typical family. Parents are also encouraged to register as carers.

"We've also updated the waiting room to make it more relevant to children and young people," reports Debbie. "There are children's jokes on the TV slides, 'Where's Wally?' posters on the wall, and more toys and books. Also, we now check with parent carers whether their youngsters would rather wait in a quieter area – or even in the garden if the weather is nice. We've put photos of staff members on the walls around the surgery as some children find it reassuring to be able to see who's who and it helps prepare them for their appointment. Children get bravery stickers for seeing a doctor or nurse as a step to building their confidence in coming to the surgery."

A new group, '**Children with Additional Needs Parent Forum**', meets bi monthly to talk and work with the surgery. The group sometimes hosts talks by professionals or has a wellbeing focus, for example with complimentary Reiki treatments. The group has a Facebook page created and managed by leading parents, Lindsey & Zoe, and this increases communication and support between meetings.

Proactive support and strengthened focus for Child Safeguarding

The surgery recognised that parents sometimes felt isolated, upset or angry before, during and after their child's diagnosis and in response put together a New Diagnosis Pack to support parents better. The pack includes an invitation to the parents and child for a 20 minute informal chat, as well as information about local services and support groups, information about the surgery, the SEND Parent Carers Support Group and information about carers.

An effective child safeguarding process had been established prior to embarking on the PACE SETTER Award but working for the Award helped develop and strengthen this still further. The child safeguarding team consists of a dedicated GP and admin lead to keep the records up to date, but it is still everyone's responsibility to report child safeguarding. The admin lead has established a positive working relationship with social workers, child access point and a very close relationship with the local health visitor team. The surgery has a child safeguarding register, a register for children considered to be at risk, an adoption register and a new under fives register

which is sent to the health visitors monthly. These registers are monitored monthly with all agencies and records are updated immediately when information is received. Updating the child safeguarding process undoubtedly helped the surgery obtain their PACE SETTER Award.

Outcomes and Benefits to having a PACE SETTER Award

GP Surgery

“Our staff are now more aware of the difficulties faced by families. The Medical Passports are a great innovation because staff can now prepare themselves before a consultation. There is definitely a better understanding between professionals and families - that gives more weight to diagnosis.”

Debbie Elcome, Practice Care Coordinator

Parent Carers

“There is now an alert on the system of my son fainting due to anxiety at having a doctor’s appointment, which was a major source of stress for us. This was a suggestion from a GP after inviting me for a double appointment to chat - very accommodating. The surgery is now more flexible about appointments, they’ve changed their perception of parent carers and conversations are easier. This surgery and GPs genuinely want to help us as parent carers.”

Lindsey Butterfield, West Sussex Parent Carer Forum Trustee and St Lawrence Surgery Parents Group

“Our main problem was there was no continuity of care ... we often didn’t know which doctor we would see until we got there ... and we often waited a long time. My son got distressed and, once called by the doctor, wanted to leave ... very stressful. Before the Medical Passport I had to explain his conditions in front of him ... not nice for my son. Since the Medical Passport we generally see the same nurse or doctor. We can wait in our car and staff come to get us or we wait in the garden and play on the scooter. This is so much calmer and I know I’m not disturbing others in the waiting room. My son needs to spin three times on the nurse’s chair before the appointment can start and now everyone knows and accommodates this. They really care – the care they give makes a huge difference to us as a family.”

Zoe Green, Worthing National Autistic Society and St Lawrence Surgery Parents Group

And the extra workload for the surgery...

“Co-ordinating the parent carers has been great as lead parents Lindsey and Zoe are easy to work with. They manage the Facebook page and I send them any extra

information they need. The workload for the children with additional needs is mostly done by me with help and support from Jo Wadey, Practice Manager.

“I can't say it's difficult as I enjoy doing it - I love the fact that we can see results from the hard work, and the positive feedback is very much appreciated. Keeps me going!”

Debbie Elcome, Practice Care Coordinator

Written on behalf of West Sussex Parent Carers Forum
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