



***'It is stressful having a child with complex needs
and this impacts on the long term condition I have'***

Parent Carers, Young People and Multiple Long-Term Conditions

December 2019

1. Executive Summary:

This consultation looks at how services for parent carers and young people (YP) who have Multiple Long Term Conditions (MLTC) can be improved.

We ran this consultation as part of Brighton & Hove Communities and Third Sector Investment Programme (TSIP), which funds Amaze and PaCC to gather views and ideas from carers around provision and delivery of health care services. Brighton & Hove Clinical Commissioning Group (B&H CCG) is looking into improving the way services and support for people who have Multiple Long Term Conditions (MLTC) are planned and delivered.

MLTC, also known as chronic diseases, are conditions for which there are currently no cure, and which are managed with drugs and other treatment, for example: diabetes, chronic obstructive pulmonary disease, arthritis and hypertension.

We are aware that many parent carers have MLTC and that some of these conditions are as a direct result of caring. We are also aware that many YP with disabilities and/or additional needs will develop MLTC later on in their life.

This report is divided into two parts, the first is about parent carers, the second is about YP. What we found out:

Parent carers

- 56% respondents reported a **negative experience** whilst accessing health and care services. Main issues highlighted were long waiting times, appointment booking systems, communication from professionals, lack of awareness of their health status and inability to get respite.
- 40% respondents reported a **good experience** of accessing services. Positive comments underlined GPs being supportive and aware of the patient carer's status and regular check-up appointments.
- Parent carers reported **challenges** in managing their MLTC: people and professionals' attitudes; system and structural issues in health and social care services; no respite being available; no support for YP; the work and welfare system; the inability to look after themselves; and shortage of suitable activities.

- Parent carers said they would like to be able to **access support from primary care** (in order of preference): more support groups, a holistic person-centred approach which focuses on them as an individual rather than a series of conditions, annual health check-ups for them, advice on how to manage stress and anxiety, resilience techniques, longer appointments and consistency of GP, support at home, better coordination of services and help with transport to appointments.
- 88% parent carers say they would like **more support around self-care and self-management**, 44% would like to be able to access more support for their carer, whilst 6% would like a nurse to visit their home
- **45% parent carers would like services to be provided at their home**, 23% preferred the GP surgery, and 32% suggested other locations for example polyclinic, a specialist hospital, work place or a nice café/venue with treatment rooms.

Young People:

- 53% parent carers reported a **negative experience** whilst accessing health and care services for their YP. Main issues included some GPs not being able to deal with demand, poor communication, services not being joined up, poor transition into adult services, systems not meeting families' needs, long waiting lists and some GPs not offering online booking for appointments.
- 41% parent carers reported a **good experience** accessing health and care services for their YP. Comments included having an excellent team around their YP and support from their GP (in spite of more negative experiences of other services, e.g. SALT, Physio, OT and Optometry).
- Parent carers reported **challenges on managing their YP's with SEND and MLTC** including difficulty on communicating YP's needs, not enough wellbeing support / support groups, an oppositional education system, general concern with the overall health care system and lack of early intervention .
- Parent carers said they would like to be able to access **support for their YP from primary care** (in order of preference): more support groups, advice on managing stress, anxiety and increasing resilience, more support at home, a holistic person-centred approach which focuses on them as an individual rather than a series of conditions, access to annual health check-ups and longer appointments with a consistent GP, help with staying healthy to reduce the risk of MLTC getting worse, advice on managing conditions/pain, how to avoid unscheduled hospital stays, better coordination between services, annual medicines review and help with transport to appointments.
- **82% parent carers would like to receive more support for their YP, 65% would like to be able to access more support on self-care and self-management**, 29% specified a desire to access a visiting nurse service for their YP. Others identified a need for training to medical professionals about managing YP with communication difficulties, for group socialising opportunities for their YP, personal health passports and annual health checks.
- **53% parent carers would like services to be provided at home**, 12% preferred services via the GP surgery, 35% suggested other non-medical locations, whilst others specified a clinic or polyclinic.

Recommendations:

- 1. Continue to improve access to information on services and support groups available for families managing MLTC, including advice on self-care and self-management**
- 2. Further encourage and support use of Personal Health Passports as a way to improve patient experience and reduce gaps between services**
- 3. Recognise the importance of families being able to access support in a variety of settings e.g. at home, GPs, clinics or non-medical locations, and seek to sustain this**
- 4. Provide training for GPs and other health professionals around how to communicate and support YP and adults with SEND who have MLTC**
- 5. All GPs to provide booking appointment system by phone and on line to improve access and reduce the stress and anxiety for parent carers and YP**
- 6. All GPs to have a system in place which flags patients with MLTC so they are routinely offered longer appointments and regular health check-ups**
- 7. Recognise families with young people and adults with MLTC as a priority group to receive more respite services**
- 8. Produce case studies to promote good practice as reported by families who have experienced positive person-centred, holistic care, for their / their CYP's MLTC**

2. Report:

2.1 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person (CYP), for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence, which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with Special Education Needs and Disabilities (SEND) themselves, up to the age of 25.

2.2 What PaCC does

The PaCC (Brighton and Hove Parent Carers' Council), hosted by Amaze, is a city-wide engagement group with over 415 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has ten partner organisations, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods, for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

2.3 This consultation

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and PaCC to gather views and ideas from carers around provision and delivery of health care services. Amaze and PaCC specifically consult parent carers of families with children and young people with additional needs and/or disability – see Amaze and PaCC engagement diagram.



The B&H CCG is looking into improving the way services and support for people who have Multiple Long Term Conditions (MLTC) are planned and delivered. This consultation engages parent carers and young people who have MLTC and it asks for their experience of accessing services.

MLTC, also known as chronic diseases, are conditions for which there are currently no cure, and which are managed with drugs and other treatment, for example: diabetes, chronic obstructive pulmonary disease, arthritis and hypertension.

One of the drivers for this consultation is that more people are now living with multiple long-term conditions and research has highlighted a need to better support people with MLTC by focusing on prevention, including access to activities and support which empowers people to self-manage their conditions.

We are aware that many parent carers have MLTC and that some of these conditions are as a direct result of caring. We are also aware that many YP with disabilities and/or additional needs will develop MLTC later on in their life.

With this consultation we wanted to find out what changes would help improve everyday living, and the future, for parent carers and their YP living with MLTCs. Suggestions and recommendations from this consultation will be passed on to B&H CCG to inform service delivery and planning.

3. Methodology

To gather data and information for this consultation we used an online questionnaire which was designed with support from Amaze's Database Coordinator. The draft was sent to the CCG to be signed off. The questionnaire included a range of questions with 'please select' and 'tick box' options and boxes to provide extra information and comments. The questionnaire is divided into two parts, the first is about parent carers, the second is for young people (YP)

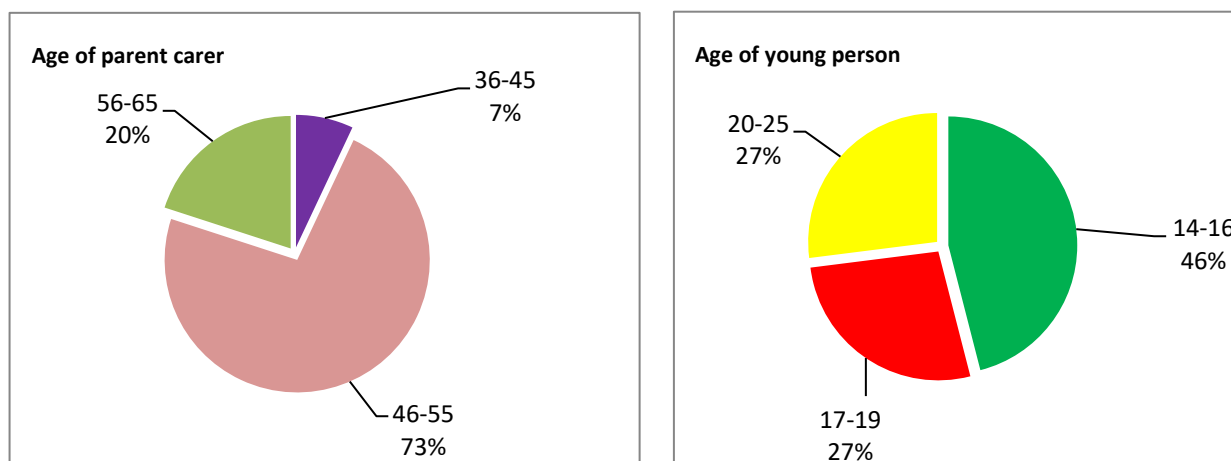


The questionnaire was sent to 2000+ parent carers in Brighton and Hove on the Compass Register, held by Amaze, and it was promoted via PaCC and PaCC Partners' social media. We received 55 completed questionnaires, which were 'summarised into a report'



Parent carers and YP's contributions to this consultation are reported in *verbatim* to ensure the detail of their experiences is captured and considered. Only some respondents' contributions are included in the report, for the full list see the 'summarised report' above.

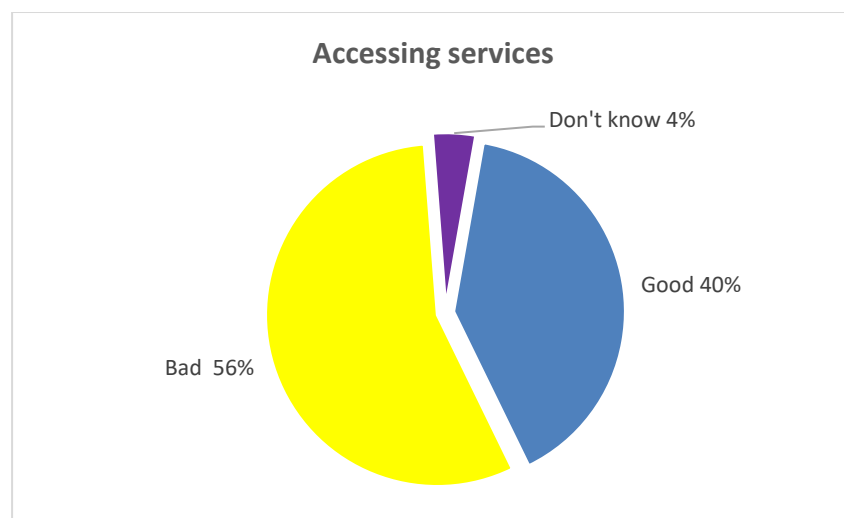
4. Demographics from the online questionnaire



5. Findings from online questionnaire – Parent Carers

5.1 Parent Carers and access to health services and care services

To the question *‘What’s your experience of accessing health services and care services’* parent carers with MLTC told us:



The **majority of respondents – 56%** - reported a **bad experience** when they accessed health and cares services. Many parent carers highlighted the **long waiting time** for an appointment. One parent commented – *‘It is a long wait to see my local GP so for example a bookable appointment is usually a 2 week wait. The last appointment I attended which I made on the day I had to wait 1 hour before I got to see my GP’* – whilst another commented on the **booking appointment system** – *‘Trying to get appointments at doctors is difficult because I am at work at the phone up times’*.

Some respondents talked about **communication and awareness** as being one of the problems – *‘It is mostly ok but communication remains a massive problem and long waits for appointments. **Some services are great at acknowledging caring responsibility but others couldn't care less**’* – and another respondent – *‘**GPs do not understand long-term conditions and do not appreciate that patients are more expert on their condition than GPs are**’*. Some parents felt not listened to and not believed – *‘Didn't believe me until it was too late. When they ran the tests they found things and apologised but it took so long that it ruined my life’* – an issue reflected by another respondent – *‘Really bad as my conditions are very complex, **I spent many years not being believed**, till I travel out of area to see specialists. It's also very difficult to have tests and medication trials when you have **no childcare**’*.

Inability to get childcare or respite has been reported as a huge barrier to parent carers accessing health and social care for themselves. One parent commented that – *‘**I don't know what is available. The Compass Card team have a list of venues accepting the compass card**’*.

40% parent carers who completed the online questionnaire **reported a good experience** on accessing health and social services. One parent feedback – *‘**I have a very supportive GP who is aware of my Carer status and is respectful of that. However I've been referred for an off loader brace for my knee (injury and osteoarthritis) and been informed it's a 4-5 month wait for the fitting**’* – and another commented – *‘**Good but it has been a struggle to get where we are now. My autistic son has transport, attends Hill Park. Outstanding help for our health conditions**’* One parent pointed out the reason of their good experience – *‘**I have check-up appointments and treatment regularly**’*

5.2 MLTC - challenges

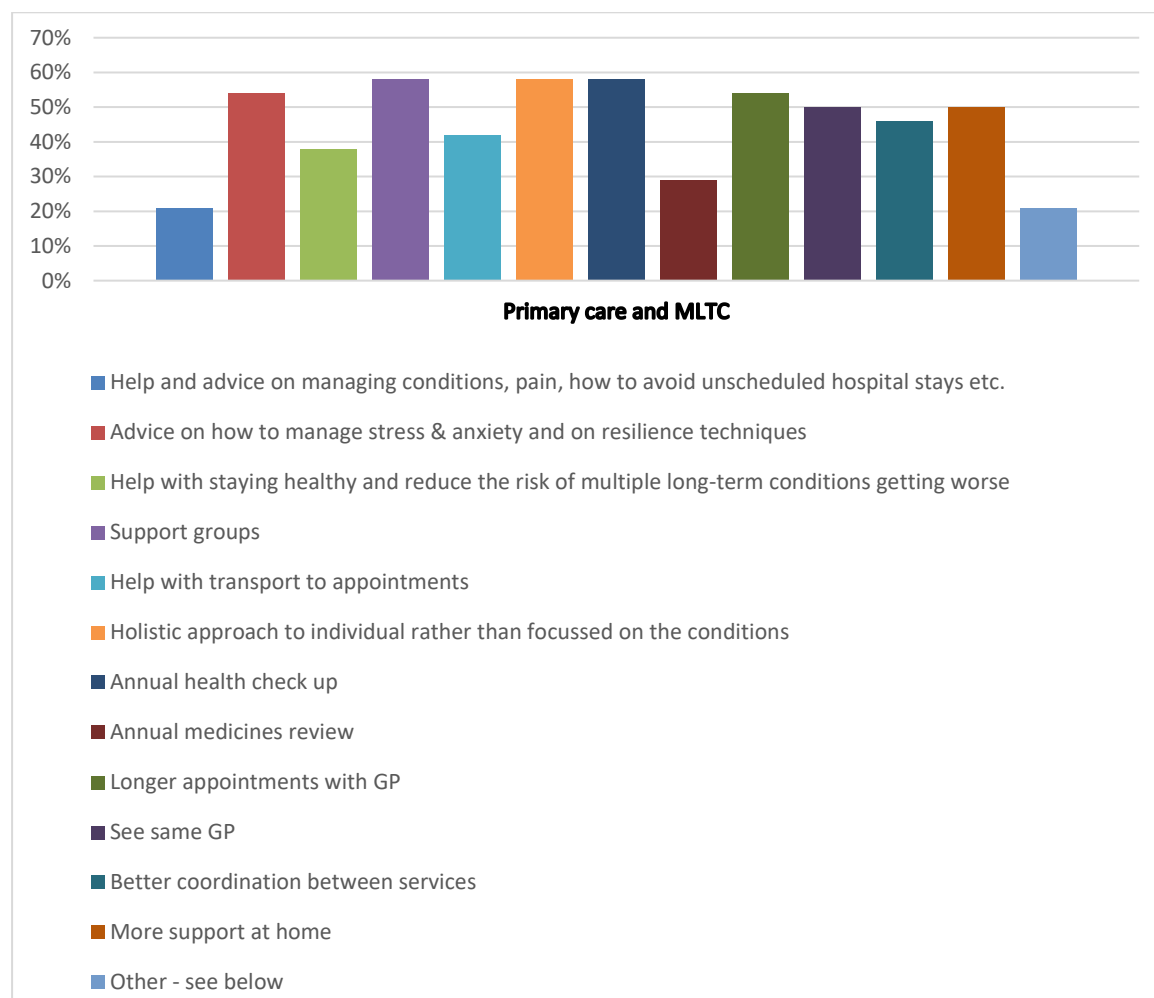
Parent carers were asked about *‘the biggest challenges they face in managing their long-term conditions and keeping well’*. We grouped challenges/comments in the table below.

Challenge	Comment
Condition and people / professionals' attitude	<i>‘It's unrelenting- constant vigilance required. The condition is invisible and so people don't realise the suffering, struggle and challenge. People can be very judgmental- including some health care professionals. It is good to find fun things to do to alleviate some of the struggle an stress’</i>
Health and social care system	<i>‘I can't get appointments or it takes months or even years to hear. The constant fights with the council for transport, blue badge, education etc. seem to be deliberately obstructive and exhausting for an already knackered Mum. Often the energy just isn't there to really take care of myself. I find Dad's are even worse off because they are expected to cope with everything even though they have physical and mental health issues too’</i>

	<i>'I have memory issues which causes issues trying to keep on top of appointments for both my son and myself and also long term mobility issues'</i>
Respite	<p><i>'No suitable respite places available so stresses on all levels are mounting up'</i></p> <p><i>'I have no respite and no school, in fact no services at all for my daughter. I have 15 different medical conditions they all need to be managed on a min to min basis and I can't do that, I get no sleep, can't eat well, can't leave the house. Can't get to appointments and tests. The way social services and CAMHS in Brighton parent blame adds to the pressure'</i></p> <p><i>'Not able to do exercises regularly as I am too exhausted from caring for my son and I don't have enough carers to look after him so I can attend a class'</i></p>
Support for YP	<i>'I can manage my health condition very well, but my challenge is that I have to struggle to get services for my teenager and that is when life becomes very tough which then impacts on myself'</i>
Work and welfare system	<p><i>'Affording things, as Working Tax Credits stop when they are 20, I have to work longer hours, which means I have even less time and struggle when I am having bad days. Due to my mobility on bad days'</i></p> <p><i>'Anxiety about my son seems to always increase my stress levels. I can't hold a full time job and get a decent wage to look after my health and provide for my son'</i></p> <p><i>'I'm carer to my 14yrs old & do everything myself which is struggle as still waiting for help even though been allowed direct payment'</i></p>
Inability to look after yourself and activities	<p><i>'Not being able to afford nice pampering treatments or even affording the hairdressers. My earning potential is reduced because of the need to be around for my ASC Son'</i></p> <p><i>'I am having trouble renewing my Carers card. I need it to make accessing leisure centres more affordable. Before this it was okay'</i></p> <p><i>'Osteoarthritis, a knee injury, chronic stress and sleep deprivation. Lack of money to pay for exercise activities that also provide the social connection and prevent isolation'</i></p> <p><i>'Motivation when I can't do the things I wanted to do. Chronic fatigue above all else. I just have so little energy to do anything even if I enjoy it which means my mental health suffers'</i></p>

5.3 Primary Care and MLTC

We asked parent carers 'How can Primary Care services, that is GPs, chemists (pharmacies), community and practice nurses, community midwives and health visitors, family planning or sexual health clinics, dentists, opticians and hearing care providers help you with your multiple long-term conditions? Please tick all that apply' Below here is what parent carers told us:



The most popular response was to be able to access more **support groups** and a person-centred **holistic approach to individuals rather than focusing on conditions**. A respondent stated – '*It would be useful if professionals involved had a better understanding of my conditions*' – and another added - '*No continuation of care or joined up support between hospital and outpatient services*'

Many parent carers would like to receive an **annual health check-up**.

Also parents would like to be able to access more **advice on how to manage stress and anxiety and on resilience techniques**, **longer appointments with a consistent GP** and **support at home**. One respondent requested – '*GP home visits and reasonable adjustment*'

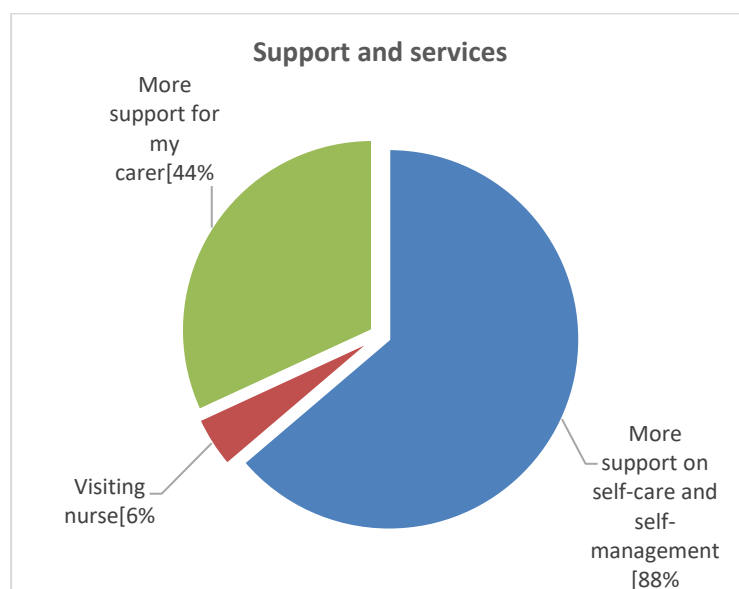
and **better coordination of services**; one parent commented – *‘Better administration. Too often prescription mistakes and other problems with appointments. GPs wanting to duplicate what specialist hospital does. Too often having to justify what is needed’*. One respondent underlined the fact that carers are not prioritised by the system – *‘Carer status is meant to be a red flag in the system I think, but in reality this doesn't seem to happen’*

Respondents would like also to be able to get **help with transport to appointments**.

One parent suggested – *‘Believe patients. All issues need to be dealt with, not just one. My neurodivergence affects my mental health affects my physical health, ignoring one means you ignore them all’*

5.4 What services and support

We then asked parent carers *‘What services and support would you like to receive? Please tick all that apply’* Respondents feedback:



The majority of respondents, **88% would like more support around self-care and self-management**. Parent carers told us that it could include – *‘I'd like faster access to Physio and any equipment that I might need to support my condition’* – as well as – *‘Very low cost treatments e.g. £10 for a 15minute head massage or homeopath treatment or foot massage, making our own aromatherapy beauty products’* - and – *‘Work place support. Support and access to activities to enjoy. Access to and training in technology to help with my condition’*

One respondent would like - *‘More support on how to cope with unpredictable young adult with poor communication skill. Advice/strategies to cope with stressful situations. Guidance in his to prepare the young adult for living independently’*. One parent carer suggested – *‘Support groups for other multiple sclerosis sufferers’* – and *‘specialist orthopaedic support’*

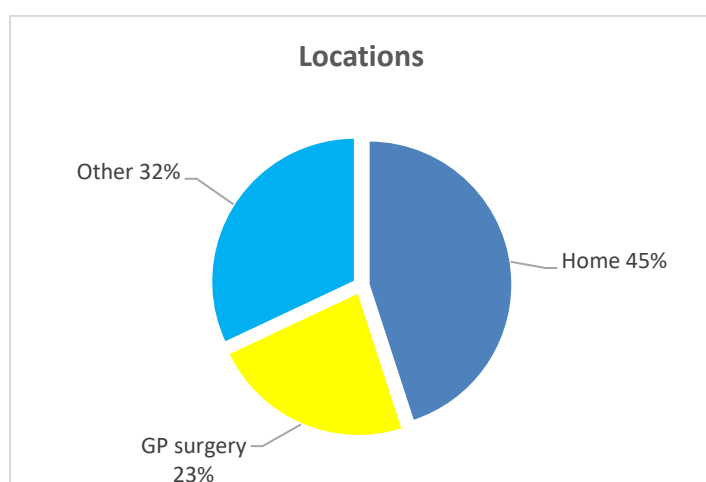
44% of parent carers would also like to be able to access more support for their carer. One parent commented – *‘What help I, the parent carer can have’*.

6% would like a nurse to visit their home, as highlighted by a parent – *‘Something more structured for those of use who mostly do not have carers or people who visit at home’* – and by another – *‘Carers support. In home health support’*

In addition to the above, parent carers suggested – *‘More help with care and respite’* – and - *‘Suitable high quality respite homes’*. One respondent reiterated the **importance of receiving good support from GP** – *‘Appropriate healthcare, GP who listens, understands and responds, GP who doesn’t breach confidentiality, GP who is flexible and understands legal duties on them’*

5.5 Locations where services should be delivered

This question *‘Where would you like those services to be delivered?’* explores what parent carers suggest the services should be delivered from:

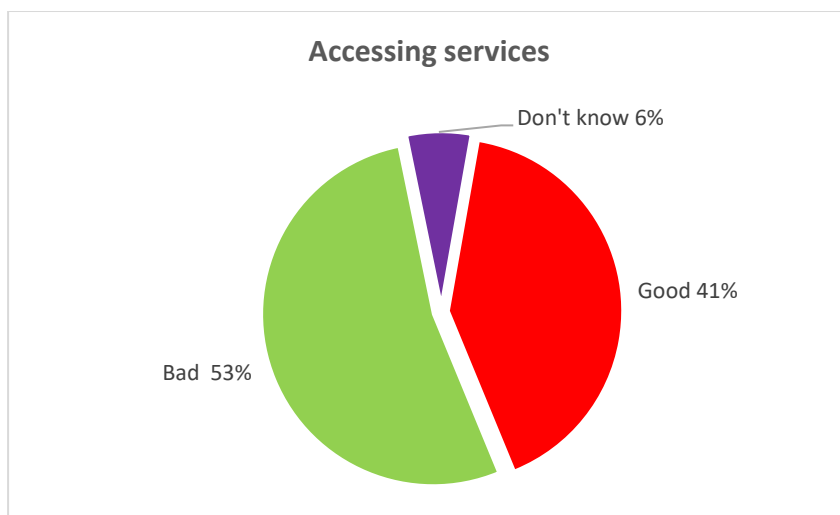


Most parent carers who responded to our online questionnaire, **45% would like services to be provided at their home**, whilst **23% suggested GP surgery**. **32% suggested other locations** as for example **polyclinic, a specialist hospital, work place** or - *‘a nice café/venue with treatment rooms only for Carers’*

6. Findings from online questionnaire – Young People

6.1 Young People and access to health services and care services

To the question *‘What’s your experience of your young person accessing health services and care services’* parent carers and some YP told us:



The **majority of respondents – 53% - reported a negative experience when they accessed health and cares services for YP**. Some parents and YP see the **issue around GPs not been able to deal with demand** – *‘Young person has autism etc. and dislikes being ill, GP says he is out of his depth and shrug his shoulders when I’m trying to get him to help’*. Several respondents pointed out **communication and not joined up services as an issue** – *‘Fantastic support from specialist London hospital. Problems with GP wanting to duplicate and interfere with the hospital work. GP not understanding the complexity of the condition’*- and – *‘Doctor/specialist don’t ask the right questions or look at the patient as a whole taking their disability into account’*.

One YP underlined how **transition into adult services has been quite challenging** – *‘I have had very poor experiences, since I left the child specialist services and was discharged to the care of my GP I have felt like a hypochondriac trying to get support. I’ve gone from 3 monthly check-ins with a specialist doctor to begging my GP to refer me to adult services or the pain clinic. I’ve also lost access to medication that has helped me as a child due to the lack of support’*

Several respondents underlined **the whole system is not delivering what the families need** – *‘Again, where do I start. Atrocious mental health care and diagnostic expertise by CAMHS. Big gaping hole that doesn’t even meet publicly stated claims, for older teenagers. Professionals unwilling to listen to parent carer and respect their expertise in their child/ren, unwillingness to admit mistakes and rectify, clear refusal to act in the child’s best interests’* Many parents would like to see **a better system** - *‘Poor. There is no follow up’* – whilst another commented on **long waiting list** – *‘The waiting list for anxiety management or relaxation strategies are ridiculously long’* – and another asked for more support for children – *‘Counselling services are needed for child mental health. The wait is ridiculously long’*

There is also a need to make sure all **GPs to offer online booking appointment** – *‘As I have to do it for them, making appointments with doctors as phone up times are while I am at work’*

41% of parent carers and YP who completed the online questionnaire **reported a good experience** on accessing health and social services. One parent commented about **support**

for their young person – **‘We have an excellent team around him’** – whilst another positively stated – **‘Always been good’**. Interestingly one parent has **praise for GP but negative experience from other services** – **‘GP is good SALT, Physio, OT and Optometry service provision is very poor for CYP with SEND’**

6.2 MLTC - challenges

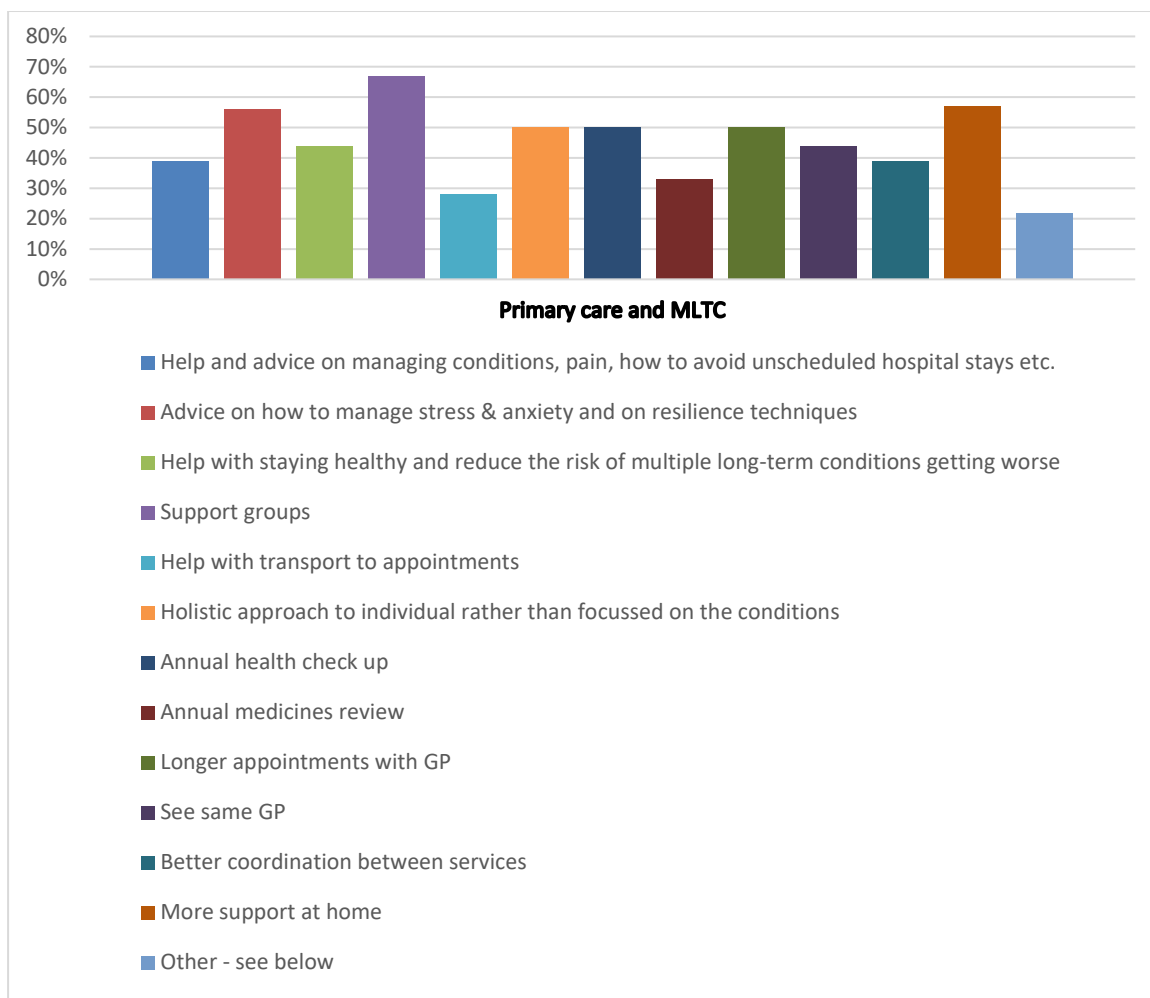
Parent carers and YP were asked about *‘the biggest challenges a young person faces to managing their long-term conditions and keeping well’*. We grouped challenges/comments in the table below:

Challenge	Comment
YP’s disability and communication	<p>‘He has poor communication, hates and denies being ill and hasn’t the capacity to make informed decisions’</p> <p>‘Not being able to go out on their own. Poor sleep’</p> <p>‘Has fear of attending hospital / medical appointments’</p> <p>‘My son is very forgetful even if he has it written down. He is finding difficult in prioritising his health and wellbeing. Has poor communication skills’</p> <p>‘Communication barrier, needs support/help. Help with getting to places/appointments’</p> <p>‘Doesn’t like waiting for appointments. Doesn’t cope well in crowded environment’</p>
Not enough wellbeing support and support groups	<p>‘Wellbeing support (fun activities, sport etc – non medical) would help. Support group of people with the same condition (but where partners, siblings and friends can also attend)’</p> <p>‘Managing conditions within peer groups’</p> <p>‘Nothing available for High Functioning Autism with Social Communication difficulties. Teach them about themselves. Also learn about their senses and how it can affect them on a day to day basis’</p> <p>‘He relies on me as his Carer and his school. Outreach is inadequate’</p>
Education system	<p>‘Pressure from school around attendance when school is missed due to appointments. Worry about the future as pressure to attend school will affect future prospects’</p>

	<i>'Fear of repercussions from missing school so will push to attend despite being unwell. Not wanting to draw attention to conditions'</i>
General health including mental health	<p><i>'Chronic pain – to help with managing this. Lack of regular appointments with specialists. Finite rehab sessions'</i></p> <p><i>'Mental health'</i></p> <p><i>'His heart is the main one which I always have to chase but also behaviour issues'</i></p>
Health care system	<p><i>'Specialist training in new technology would help'</i></p> <p><i>'Getting referred when relapses happen and no one checking in . I am an expert on my own condition and I feel like I'm treated like a drug seeker. All the GPs I've seen never want to know or investigate new worrying symptoms that impact my everyday life'</i></p> <p><i>'Lack of autism awareness by professionals, professional unwillingness to listen to and respect parent carers, professional unwillingness to correct mistakes and awareness of legal duties they must comply with'</i></p> <p><i>'No access to chronic incurable condition support within HNS cannot afford private health care'</i></p> <p><i>'Long waiting lists, no ongoing support. No one is willing to work out what services might benefit me'</i></p>
Lack of early intervention	<i>'The lack of vital early intervention around SALT and Physio which should be lifelong if needed. Services are too quick to take our CYP off their books when they are barely managing'</i>

6.3 Primary Care and MLTC

We asked parent carers *'How can Primary Care services, that is GPs, chemists, etc. help your young person with their multiple long-term conditions? Please tick all that apply'* Below here is what parent carers and young people told us:



67% of parent carers who responded to this question would like to **be able to access support groups**, as one person suggested - *'Groups for teenagers'*. **55%** would also like to **receive advice on managing stress and anxiety and advice on resilience techniques**, one person suggested - *'access to wellbeing activities that can include partners, friends and family'* - as well as **more support at home**.

Approx. **50%** stated that they prefer **a holistic person-centred approach to an individual's need instead of focussing on their conditions**, specifically one respondent proposed - *'More knowledge of conditions. Offering support services. Better information about managing conditions. Talking to the young person as the expert in their condition'* - and other commented - *'I have had poor experience in the past from doctors who do not seem to understand my sons mental health conditions'*

They would also like to **access annual health check-ups and longer appointments with their GP**, a respondent pointed out - *'Follow up with young person as they are forgetful, ask suitable questions'*. Another person suggested that - *'GP needs to be given time to learn about rare diseases affecting registered patients and have good understanding of local and national support providers'*.

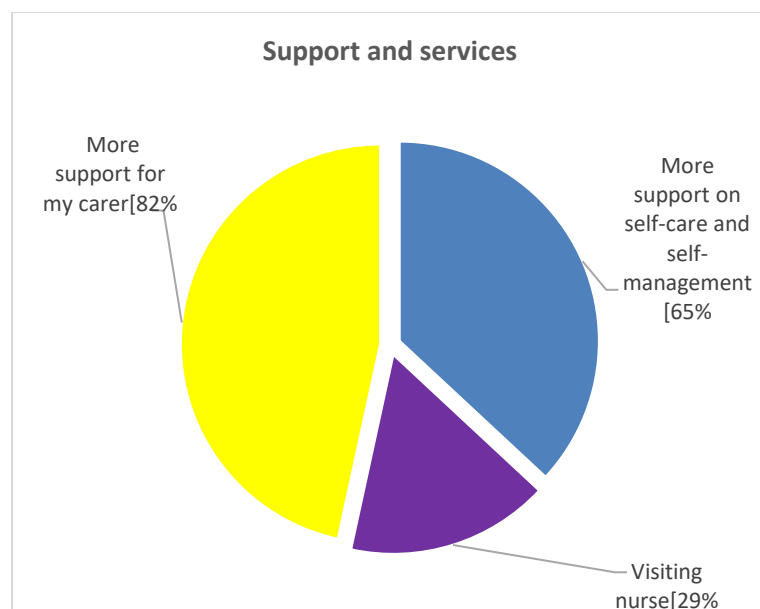
44% parent carers requested that their YP be able to be seen consistently by same GP and get help with staying healthy and reduce the risk of MLTC getting worse. One person commented - 'If there could be a way to highlight a name in e.g.: the colour green, to highlight that someone has Autism which alerts the Receptionist/Doctor to the fact that our kids find it hard to wait and do not like being in a crowded waiting room'

Other suggestions included help and advice on managing conditions, pain, how to avoid unscheduled hospital stays etc. and better coordination between services, reiterated by a respondent - '*Faster communication from hospital consultants back to GPs, especially about medicines/prescriptions*'. Some respondents suggested annual medicines review and help with transport to appointments.

One respondent summarised some of the suggestions above - '*Having a disability passport that you can share with doctors that has an agreed plan of action in case of relapses would be good*'

6.5 What services and support

We then asked parent carers and YP 'What services and support would your young person like to receive? Please tick all that apply' Respondents feedback:



82% of respondents would like to receive more support for their carer. One YP stated - '*Wellbeing support for self and carer*' - whilst a parent carer mentioned - '*Clearly parent carers with health issues who are inadequately supported means that parent carer has less strength to deal with the cared for individuals' needs*' - and another YP - '*Respite and more activities*'.

65% of people who completed the online questionnaire would like to be able to access more support on self-care and self-management. In particular, one respondent mentioned -

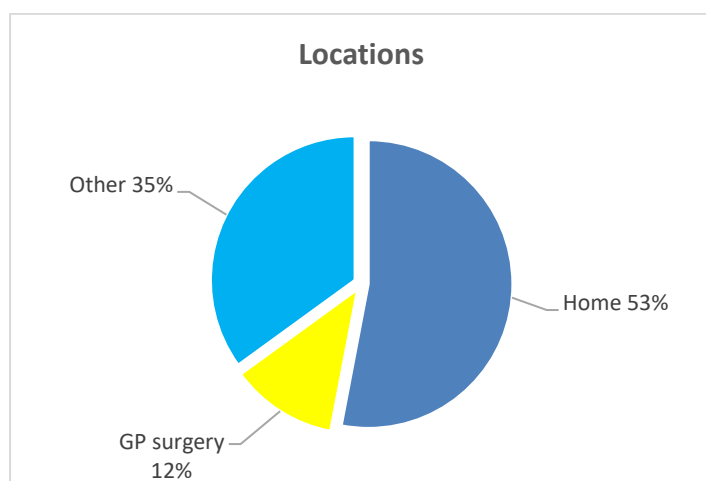
'Anxiety management strategies. The importance of self-care. Teaching about sensory feedback and overwhelm' - and a parent carer would like to receive - **'More interventions around his mental health'**

29% recommended a **visiting nurse** as a service/support they would like to receive.

Among 'other' services that YP would like to receive, some respondents suggested - *'It would be great to offer training to medical professionals about managing young people with communication difficulties'* - also groups and socialising and - *'Having a Personal Health Passport'* - and **annual checks** to review the YP's progress.

6.6 Locations where services should be delivered

This question 'Where would your young person like those services to be delivered?' explores what parent carers and YP suggest the services should be delivered from:



53% of parent carers would like services to be delivered at home, whilst **12%** would prefer to go to the GP surgery to access services. In addition **35%** of respondents suggested other non-medical locations as for example - *'a group work situation for Parent Carers and their young person'* - or medical environments like clinic or polyclinic.

7 Recommendations

- 1. Continue to improve access to information on services and support groups available for families managing MLTC, including advice on self-care and self-management**
- 2. Further encourage and support use of Personal Health Passports as a way to improve patient experience and reduce gaps between services**
- 3. Recognise the importance of families being able to access support in a variety of settings eg at home, GPs, clinics or non-medical locations, and seek to offer this**
- 4. Provide training for GPs and other health professionals around how to communicate and support YP and adults with SEND who have MLTC**
- 5. All GPs to provide booking appointment system by phone and on line**
- 6. All GPs to have a system in place which flags patients with MLTC so they are routinely offered longer appointments and regular health check-ups**
- 7. Increase respite available for those families with young people and adults with MLTC**
- 8. Produce case studies to promote good practice as reported by families who have experienced positive person-centred, holistic care, for their / their CYP's MLTC**