IMPACT OF COVID-19 ON LEUKODYSTROPHY

PATIENTS AND THEIR FAMILIES
During June 2020 Alex TLC surveyed beneficiaries to assess how they have been coping with lockdown. We wanted to assess the key issues affecting our community and whether Alex TLC support during lockdown had been useful. 28 beneficiaries responded to the survey, reflecting the views of approximately 84 individuals affected by leukodystrophy*.

*Assuming the average family size of each respondent is 3
GUIDANCE AND INFORMATION

Have you been given clear advice and guidance from the NHS about whether or not you/the person you care for/family member are at higher risk of severe illness due to Covid-19?
28 responses

- Yes: 75%
- No: 25%

Do you feel you have access to reliable information regarding Covid-19 that relates to the condition that affects you?
28 responses

- Strongly agree: 10.7%
- Agree: 42.9%
- Neither agree or disagree: 17.9%
- Disagree: 17.9%
- Strongly disagree: 10.7%

Have you received a letter from the NHS advising you that you are in the extremely vulnerable category?
28 responses

- Yes: 28.6%
- No: 71.4%
“Information given from NHS and Alex TLC nice and clear, however government information can be misleading and unclear”

“Addison’s group information on dealing with illness/crisis”

“Spoke to Karen (Support Services Manager) with concerns I had”

“I received information about how to treat an Addisonian crisis triggered by covid-19 from our endocrinologist”

“Steroid Emergency Card (Adult); Adrenal Crisis Information; Phone call (from Karen, Support Services Manager) informing us about injection kit we require. First class information. The information was not new to us, but it all served as a ‘wake up’ call to be fully prepared. That kind of response lets us know we are not alone with our rare genetic problems. The Emergency Card (Adult) was particularly helpful.”

“My family members have multiple issues that would make them extremely vulnerable to Covid-19 we were surprised that they did not receive a letter”

Three quarters of respondents had been given clear advice on their risk factors as to Covid-19 and had received a shielding letter. However only just over 60% of respondents felt they had access to clear advice about their condition and associated risks. Alex TLC’s information was clearly the most useful information for respondents, with Government and NHS advice also widely used.

It is imperative we maintain regular updates to this information for our beneficiaries.
CARE AT HOME

Has lockdowm affected your existing home care package?
28 responses

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<th>Yes</th>
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<td>57.1%</td>
<td>42.9%</td>
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What changes have you experienced as a result of lockdown?
12 responses

- My care package has reduced due to a lack of carers (number of hours allocated has remained the same)
- I have suspended my home care package due to the risks of infection
- There has been no change to my home care package

Respondent comments

“Our son’s team of carers has reduced from 6 to 2 people and they are working reduced hours”

“Old receive weekly shop”
SUSPENDING YOUR HOME CARE PACKAGE

If you have suspended your home care package, what advice has your local authority given about reinstatement?
11 responses

- 54.5% Confirmed home care package will be reinstated at same level
- 9.1% Home care package will be reassessed before resuming
- 36.4% No advice has been given

Respondent comments

“No day or night-time respite”

“Our son still receives care every day, but the number of hours has reduced because there are only two carers”

“We are shielding so could not risk unnecessary people coming to the home”

“Our arrangement is with a local Care Company. One young man comes in for one-and-a-half hours twice a week. He provides company for our 30-year-old son, and some help with his shaving etc.”

Alex TLC comments and conclusion

We can assume from the response to the question around care package changes and the subsequent small number of respondents reporting no changes to care packages, that around 50% of respondents do not require a home care package. Of those that do, the majority have either suspended their care package due to infection risks or it has been reduced due to lack of carers. It is concerning that over half of those with reduced care packages have not been advised if these will be reinstated at previous levels.

Alex TLC will monitor this situation carefully and ensure we are fully informed on local authority responsibilities and processes, in order to effectively support those who may experience difficulties.
HOSPITAL APPOINTMENTS

How concerned are you about attending hospital for the following reasons?

Have any medical appointments been cancelled or postponed?
28 responses

CANCELLED & POSTPONED APPOINTMENTS

If your appointment has been postponed, are you happy with the new date?
20 responses
Respondent comments

Still do not have new dates for many of my appointments and surgery.

No new date given. Had another scheduled telephone consultation and despite the emails, letters and texts about this appointment it never happened - no one phoned

I had an appointment with endocrinology this has not been rescheduled

I have had a neuro-physiotherapist appointment cancelled and not yet been remade. I have also had an endocrinology appointment cancelled, which the doctor got in touch with me and has sent a letter along with a request for blood tests with a new appointment to be made within 6 to 8 months

If your appointment was cancelled, were you offered an alternative such as a telephone or virtual appointment?
20 responses

How helpful was having a telephone or virtual appointment?
10 responses
Respondent comments

“The adrenal insufficiency nurse phoned our son to check he was fully informed about his prednisone tablets, and what to do in an emergency. Alex TLC had previously dealt with this online. So, we had ‘back up’ from two sources. The Alex TLC information came immediately and was the most reassuring help there possibly could be.”

Alex TLC comments and conclusion

Not unsurprisingly, the majority of respondents have concerns about visiting hospitals for any reason during the pandemic, with a majority very concerned about A&E admissions and visiting. Three quarters of respondents had appointments cancelled, with only 55% happy with the new dates arranged. It has been encouraging not to have had reports of routine monitoring such as MRI scans being cancelled or postponed. Of some concern is that only half of those with cancelled appointments have been offered appointment by alternative means such as telephone or video appointments. However, of those that have accessed these, 80% found the consultations helpful. Alex TLC advice seems to have been well received, particularly with regard to adrenal insufficiency. Alex TLC will remain alert to reports of issues around routine monitoring and liaise with NHS contacts where appropriate.
Have you or a family member been diagnosed, or suspect you have had or currently have, Covid-19?
27 responses

- Yes: 3.7%
- No: 96.3%

Respondent comments

“My son got very mild symptoms lasting a few days (he has ALD) this went on to me and my husband becoming infected quiet badly with full blown symptoms for over 10 days but no hospitalisation required very tough time”

In general, how well are you/your family coping with Lockdown?
28 responses

- Lockdown is extremely difficult, not coping at all: 7.1%
- Lockdown is difficult, just about coping: 42.0%
- Lockdown is a little difficult, coping ok: 17.9%
- Lockdown is not at all difficult, coping well: 32.1%
“My children have been unable to see/stay with their father for 3 months. Emotionally is has been very difficult”

“We are very worried about schools reopening as a family member is a teacher. 3 of us have ALD and are shielding, so concerned about him bringing Covid back from school. He is a carer so can’t socially distance.”

“Isolation is extremely hard”

“Our son, with adult cALD and AMN, is missing his outside company from friends and carers”.

“It is very difficult for everything, safety, transformation, scary socializing with other people, always do a social distancing to buy needs,”

“Loneliness isolated unable to work”

“I’ve struggled enormously with not been able to see my boy! We have been face timing loads, but not the same! And his speech is so bad was hard on face time, but we managed! Us humans are adaptable if we just go with it, rather than fight it I guess! BUT after 14 weeks I saw him for the 1st time this week! 2 metre rule! But was great! And took the dogs with me to!!! And his brother!”

Are you/your family suffering with depression/anxiety/feelings of loneliness and isolation due to lockdown measures?
28 responses
Respondent comments

“We are all a bit depressed”

“We are fine apart from the worry about schools reopening. There seems to be a gap in logic, in that somebody living with three shielding people don’t need to shield with them.”

“We are suffering from mental health conditions no support only from the HP via the telephone”

“Support only from immediate family via phone”

“Obviously have bad days like everyone has, but you just work through the day and pick yourself up.”
Now that Lockdown measures are being relaxed, how has this affected your levels of anxiety?

- Extremely anxious: 39.3%
- Moderately anxious: 17.9%
- Not anxious at all: 10.7%
- Less anxious: 32.1%

Have you accessed Alex TLC support during Lockdown?

- Yes: 60.7%
- No: 39.3%

What information and support have you accessed from Alex TLC?

- Alex TLC’s Covid-19 website page: 8 (28.6%)
- "In Conversation with Karen" episodes: 9 (32.1%)
- Health Unlocked Forum: 4 (14.3%)
- I have contacted Support Services for s…: 2 (7.1%)
- No information or support accessed: 12 (42.9%)
Respondent comments

“Karen (Support Services Manager) has been extremely helpful in getting a shielding letter for one of our Sons. He had received phone calls from the shielding service, but no letter.”

“They (Alex TLC) are my lifeline full of knowledge and they UNDERSTAND”

“The online information has been excellent. We even had a personal phone call from Karen, (Support Services Manager) which was much appreciated. This level of support is such a help with a rare condition. Alex TLC certainly addresses the care and attention needed, which the NHS cannot supply. Our contact with our local GP is very sparse.”

“I received a message from Alex TLC who had the knowledge”

Alex TLC comment and conclusion

We were pleased to see that only 1 respondent had experienced a diagnosis of Covid-19. However, lockdown is obviously a huge impact for respondents with 7% not coping, 32% just about coping, 43% coping ok and only 7% coping well. Difficulties experienced included loneliness and not seeing family and friends. 50% had depression, anxiety and feelings of loneliness as a direct result of lockdown, with the majority receiving no support.

When asked about the relaxation of lockdown rules over 70% reporting extreme and moderate anxiety. 40% of respondents had accessed Alex TLC support with a majority finding information and support via our website and social media channels. 4 respondents had accessed our peer support network and two had sought direct support from the Support Services Manager.

There is a slight concern around respondents who reported a lack of knowledge of our support service. This is being addressed through the adoption of a Digital Support Strategy as a direct response to the pandemic, and targeted work to improve communications around the support we offer is a priority. Consistent praise for the Support Services Manager throughout the survey demonstrates the high regard for Alex TLC support services when accessed.
WORK & SCHOOL

Are you or anyone in your household a key worker or continuing to work outside the home?
28 responses

- Yes: 82.1%
- No: 17.9%

Respondent comments

“I am my son's full time carer, my husband lost his job during this pandemic”

Are you or anyone in your household worried about job loss?
28 responses

- Yes: 60.7%
- No: 39.3%

Have you or anyone in your household been furloughed?
28 responses

- Yes: 75%
- No: 25%
Respondent comments

“Job losses will lead to financial concerns”

“My ex-husband had to give up his job to move back into the house in March to support my daughter who has complex medical needs and her siblings. There are some care tasks that I cannot carry out due to my own physical disabilities I asked whether he could be added to my daughters NHS care package and be paid for his support as he has his own household costs. She received 7 waking nights per week and her carers were continuing to be paid but not providing the support as I deemed the risk to high i.e. one carer also worked at A&E. This was refused three times until my local parish council intervened and is now being considered.”

“Finding a job after Covid”

“Obviously now need to build my business back up, and thankfully a lot of my customers have gone back to work, or are getting work in themselves, so starting to trickle in now.”

Do you have financial concerns?
28 responses

64.3% Yes
35.7% No

Respondent comments

“I have lost my job, so money is tight. I have managed to get a payment holiday on my mortgage”

“Not yet but we are concerned for the future”

“Are lodger and rent paying daughter but moved out because of the infection risk.
5/7 week with no money awaiting Universal credit having to use food bank and family for food”

“Need work to pick up to pay myself, managed so far, but it’s the knock-on effect.”
Are you home schooling?
28 responses

Are you concerned about your asymptomatic or unaffected children returning to school?
10 responses

Respondent comments

"More so than my daughter returning to her school."
Children with an EHCP

Does any child in your household have an EHCP (Education, Health Care Plan) 
10 responses

- Yes: 70%
- No: 30%

Children with an EHCP

Have you been contacted to discuss your child’s return to school? 
7 responses

- Yes: 57.1%
- No: 42.9%

Have you been told what measures and support will be put in place to ensure your child’s safety? 
7 responses

- Yes: 100%
Alex TLC comment and conclusion

A third of respondents were worried about job losses and finances, with some having to make difficult financial choices due to infection risks. 60% were concerned about the return to school with over 70% of these concerned about unaffected siblings returning to school and subsequent infection risks for their affected children or relatives. Of those that had an EHCP, over half had not been contacted about a return to school and no respondent had been informed about the measures that would be taken around safety measures.

Alex TLC will monitor these issues carefully and ensure we are fully informed, in order to effectively support those who may experience difficulties. We will take decisions over reinstatement of our Grant Programme, currently suspended due to our own financial situation, over the coming months.

Additional respondent comments

“Some really positive family time. But all vigilant and taking shielding seriously. One out of 4 adults working (at home) but all supportive. We know we are very fortunate, and we hope to stay well.”

“I am not sure what is going to happen as we are all aware, but in essence we are just trying to get on with it”

“We have recently moved from England to Scotland (30/1/20) and shielding for ALD is not on the Scottish list of conditions for shielding. We are in limbo waiting for new appointments for endocrinology and neurology. It’s not hugely urgent at present but the timing of our house move could have been better timed! Karen (Support Services Manager) at Alex was EXTREMELY helpful. Thank you”

“Our son with cALD/AMN has impaired vision and confined to his wheelchair. He has operated as usual, e.g. listening to ‘Talk Sport’ on his radio. This is his lifeline.”

“More time to bonding with my kids, but I am always scared for their safety”

“Miss information on the news, social media very worrying”

“Lockdown has been the weirdest thing ever! “