In May 2019, encouraged by leukodystrophy specialists, ALD Life changed its name to Alex, The Leukodystrophy Charity, in order to extend their expertise supporting those with the most common leukodystrophy, Adrenoleukodystrophy (ALD), to all affected by genetic leukodystrophy.
INTRODUCTION

The ALD Life Impact Survey 2018, distributed in September 2018, gathered the views of those supported by ALD Life from around the world. Respondents ranged from those who have only accessed our website and online information to those who have attended our Community Weekend events or received direct support.

“ALD Life was a lifeline immediately before and after diagnosis”

“ALD Life [is] essential for making valuable connections and getting support”

“Great info, great to know there’s always someone there to speak to”

The survey asks for feedback on all elements of our support work, including seeking suggestions for improvement and new areas to focus on. We also asked questions about respondents’ diagnostic journey, their experience of the public and professional knowledge and awareness of ALD, and feedback on services such as genetic counselling which are not provided by ALD Life. This will allow us to illustrate areas in need of improvement beyond our own services, helping us to highlight issues and drive change.

Feedback in the survey highlights the many strengths of ALD Life as a valuable source of support for those coping with ALD, as well as identifying avenues of further work. We would like to thank all those who took the time to complete it.
METHODOLOGY

The Survey used to gather the opinions of those who have been supported by ALD Life was developed by the ALD Life Monitoring, Evaluation and Research Officer, in consultation with the Support Services Manager and Chief Executive Officer and with reference to our most recent previous survey, the ALD Life Beneficiary Survey 2016. The increased focus of the impact of ALD Life services in the 2018 survey reflects a move towards a better understanding of strengths and weaknesses of the charity.

Once an initial draft had been made, this was circulated to our Steering Group. The valuable feedback provided by this group led to important changes to the final version of the survey.

52 individuals completed the survey; a question on how many people with ALD/AMN they care for shows that responses represent at least 95 people. This is an increase in participation from the 2016 Beneficiary Survey.

The survey was distributed to those we have supported via email, as part of our eNewsletter, through social media and through advertising on the Health Unlocked patient forum. This allowed us to reach the maximum number of respondents.

Survey respondents were asked questions about their location, their own condition, and the condition of those they care about where applicable. This allows us to report on feedback responses by different demographics. Respondents were not required to leave their name or email address.

Results of the survey as outlined in this report will be used to improve the services and support provided by ALD Life. The numerous positive responses and comments received will be used for marketing and fundraising purposes, to celebrate our achievements and promote further success. All respondents were asked if comments could be used anonymously for these purposes; those who did not agree to this will not have their comments featured in this report or used elsewhere. This number was 6% of the total (3 respondents, figure 1).

Figure 1: Consent for ALD Life to use comments
DEMOGRAPHICS

While our support services and Community Weekends are based in the UK, ALD Life receives and responds to support requests from around the world. Since the foundation of the charity, we have supported people from 42 different countries across six continents.

The chart below (figure 2) shows how far the respondents of this survey and our 2016 survey represent those we support with regard to their location. While a significant percentage (31%) of our database lives in North America, just 6% of our 2018 survey respondents live in this region. This is similar to the 2016 survey, in which 10% of respondents were from North America, and could be due to the high levels of support available from US-based ALD support groups.

Conversely, a disproportionate percentage of our UK-based beneficiaries responded to both surveys. This is more easily explained: as ALD Life is based in the UK, with the Community Weekend and face-to-face support exclusively offered here, these beneficiaries are likely to have more contact with and feel more affiliated to the organisation.

This increased connection with ALD Life by those based in the UK will be explored further in this report, in order to determine whether respondents in the UK report a more significant impact or better impressions of ALD Life.

Figure 2: Location of survey respondents relative to total supported by ALD Life
Those who responded to our survey include those coping with their own ALD and AMN symptoms, those caring for others with symptoms and those who care for others whilst also managing symptoms of their own. Almost 40% of respondents (19 people) have lost someone to ALD or AMN.

Figure 3 shows how respondents to the survey reported their own conditions.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Count (% of respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female carrier, no symptoms</td>
<td>14 (27%)</td>
</tr>
<tr>
<td>Female with AMN and symptoms</td>
<td>21 (40%)</td>
</tr>
<tr>
<td>Male with AMN</td>
<td>11 (21%)</td>
</tr>
<tr>
<td>Unaffected friend, relative or carer</td>
<td>6 (12%)</td>
</tr>
</tbody>
</table>

Options for males with symptomatic and asymptomatic ALD (with and without Addison’s Disease, having had a Bone Marrow Transplant or not) were also available. None of our respondents selected these options – this was an expected outcome, reflecting the young age of and difficulties faced by these males and shown in all previous ALD Life surveys.
The chart below (figure 4) shows the relationship between the condition of the respondent and that of those they care for. Respondents selected multiple options to describe the condition of those they care for, in order to report if a BMT had taken place, if Addison’s Disease is present and if the family had lost someone to the condition. Those selecting ‘None of the Above’ are those with their own symptoms who do not care for others with ALD/AMN.

Only one male with AMN reports caring for someone with symptomatic ALD; this relates to a brother who passed away in childhood. This tendency for carrier or affected women to report caring for those with ALD is due to the X-linked nature of the condition: females with AMN have a 50% chance of passing it on to sons who can develop the condition in childhood; sons of men with AMN do not inherit the condition.

An unaffected individual may care for someone with ALD/AMN, for example in the case of a father caring for an affected son.

Figure 4: Condition of respondent and those they care for

![Condition of respondent and those they care for](image_url)
Another important factor to consider is when the individual or family received a diagnosis of ALD, and when they first contacted ALD Life.

As shown in figure 5, the majority of respondents (60%) first contacted ALD Life over 5 years ago. 10% of respondents have never directly contacted ALD Life – these individuals have used the ALD Life website.

Considering when an individual first contacted ALD Life will help us to understand the long- and short-term effects of ALD Life support: are our services valued more highly by those who found us years ago and may no longer need our support, or by those who have come to ALD Life more recently? It is important to note that 2 of the 4 respondents who first contacted ALD Life this year (and 1 of those whose first contact was 1-2 years ago) are not newly diagnosed. These people may hold opinions of their/their loved one’s care based on experiences before they contacted ALD Life.
DIAGNOSIS AND GENETIC TESTING

While some respondents reported a diagnosis of ALD/AMN made at the same time or within months of identification of the first symptoms, others waited years to get an accurate understanding of their/their loved one’s condition.

Among respondents to this survey, the average time between first symptoms and diagnosis was over 6 years.

57% of respondents initially faced misdiagnosis, with Multiple Sclerosis (MS) the most common of these among adults. Children with ALD would be highly unlikely to be misdiagnosed with MS. The diagnosis of MS often included diagnosis of meningitis, septicaemia and salmonella. In many cases, the symptoms were simply ascribed to an “Unknown Condition”.

In describing the diagnosis, respondents report being angry and frustrated at missed opportunities to identify the condition, such as the diagnosis of a relative. Some have been left heartbroken and devastated by the effects this has had on their family.

Those who were diagnosed more quickly or without serious consequence comment on feeling lucky, or even feeling “huge and massive relief” at having questions answered.

21% of respondents mentioned family history and genetic testing in their comments around diagnosis; either as the factor which prompted diagnosis or as a missed opportunity.

Genetic counselling, or support, information and advice relating to an inherited condition found to run in your family, is of great importance for a condition like ALD, where early diagnosis is crucial for life-saving treatment. Once an ALD diagnosis is made, medical professionals should arrange genetic counselling for relatives to test for ALD and to discuss the consequences of this for current and future generations.
For the majority of survey respondents, genetic counselling was offered and received following diagnosis, as shown below (figure 6). Results in the UK, as shown in figure 7, were very similar.

![Figure 6: Genetic Counselling](image)

![Figure 7: Genetic Counselling (UK only)](image)

Just 3% of those receiving genetic counselling rated this as “Poor”, with 67% giving it a “Very Good” or “Good” rating.

80% of those receiving genetic counselling had the need to contact relatives discussed with them. Where this was not discussed, contacting relatives was either not appropriate or was suggested by those receiving counselling in 4 of 6 cases. There were only 2 cases in which contacting relatives was neither discussed nor arranged.

Comments on quality of genetic counselling received vary. One respondent notes that this allowed their daughter to have PGD (pre-implantation genetic diagnosis) to prevent ALD from being passed on. Others reflect that although steps were made towards testing relatives, the relatives rejected these for “fear of repercussions on employment, insurance, mental health”. For some, this lack of engagement of relatives had tragic consequences.

While some described support provided by genetic counsellors as “excellent”, others express concern that there was “no urgency expressed re contacting other relatives”, or that services were “quite limited”.

Genetic counselling services in the UK and around the world are not shown to be consistently high quality and do not always make efforts to inform relatives about the need for testing. ALD Life will continue to work to improve this and will explore new means to do so.
Respondents were asked to rate the importance of various services in supporting them with their/their loved one’s ALD/AMN. ALD Life were rated highly here, with 80% of respondents giving a rating of 4 or 5 out of 5. This was the joint most important source of support, with lead medical professional and ALD specialists also achieving 80% of 4 or 5 ratings, shown in figure 8, below. Family and friends were also important, with 78% of ratings of 4 or 5.

Ratings of ALD Life rise only slightly when considering only those based in the UK, as shown in the table below (figure 9), with none giving a rating below 2 out of 5. The percentage giving a rating of 4 or 5 rises to 83% (although this is the same for the rating of lead medical professionals by UK respondents).
When asked for comments on this support, many expressed frustration at the lack of knowledge of ALD and AMN amongst professionals.

“The lack of knowledge and awareness regarding the disease is huge”

Getting the right support was described as a “wearisome battle”.

The need for more help was also highlighted: “Need all the knowledge and help that we as a family can get”

On the other hand, many respondents praised those who have provided them with support, including ALD Life

“ALD Life gives both practical and emotional support”

“Other people with ALD and AMN are essential in helping me cope”

“My wife is my pillar of strength”

“Although my GP does not know a great deal about the condition, they are immensely helpful”

“ALD Life was a lifeline immediately before and after diagnosis”
SERVICES’ LEVEL OF KNOWLEDGE

Respondents typically rated the knowledge of ALD specialists and lead professionals most highly, as shown in figure 10 below, in which 70% of respondents rate the knowledge of this group either “Very Good” or “Good”. In the UK (figure 11), this figure rises slightly to 73%, with no one reporting the knowledge of ALD specialists in the UK as “Very Poor”.

![Figure 10: Rating level of knowledge by service providers](image1)

![Figure 11: Level of knowledge by service provider (UK only)](image2)
ALD Life works to improve knowledge and awareness of ALD among the public and across these services. Over the past 5 years in particular, we have focused on making connections with ALD specialists and raising awareness within the medical community, allowing us to ensure that we have the highest quality information and that we are able to connect those with ALD/AMN to relevant specialists. The success of this is shown by survey results on the level of knowledge of ALD specialists compared to the time of first contact with ALD Life, shown below (figure 12).

As marked in the above graph, 0% of respondents who first contacted ALD Life within the last 5 years rated the level of knowledge of ALD specialists as ‘Poor’ or ‘Very Poor’. This improvement cannot be wholly accredited to ALD Life but does show progress towards the aims we have been working for. This compares to results rating the level of knowledge of social services (figure 13, below), which show no improvement based on the year of first contact with ALD Life: this is an area in clear need of improvement but has not been a priority for ALD Life.
Lack of knowledge of ALD and AMN by various professional services is a common theme of our survey results, with 13 people highlighting this as the most significant barrier they face in relation to ALD or AMN. Others mention this indirectly through comments on poor coordination and information sharing between service providers.

“Most GPs and Doctors have never heard of AMN or ALD”

“My doctor...tells me that I may have to educate other health care professionals”

“I am treated as MS sufferer by medical profession as they do not know anything about AMN”

Respondents also took this opportunity to raise concerns about aspects of the condition that they feel are particularly overlooked: notably the **transition from child to adult services** and **studies and treatments into how the condition affects women**.

Fears about deterioration of their own or loved ones’ conditions also feature prominently in this question. This fear, of “the future. How fast it will develop. The unknown!” may have an effect on the mental health of those with ALD or AMN, or those caring for people with these conditions.

One respondent expressed the challenge of “helping my children grow into well-adjusted adults after what they have lived with”.
Coping with a debilitating health condition, or caring for someone with such a condition, can have a damaging effect on an individual's mental health. As a support organisation, this is an important area for ALD Life, as we seek to improve mental health and emotional wellbeing by providing compassionate, professional and practical advice and support.

While many raised concerns around their/their loved one's mental health, many had not received support for this. 44% of respondents had neither requested nor been offered mental health support, with 7% of people requesting support that they did not receive (see figure 14, left).

Stress, frustration, anxiety and depression are common themes of comments relating to the mental health of those coping with their own/their loved one’s condition. Uncertainty was a common theme, causing fear of the future.

When considering their own condition, respondents described their situation as “stressful due to uncertainty of speed of progression”. This also had an effect on their loved ones:

“They worry about me and don’t know how to help”.

Caring for a loved one with ALD or AMN can also cause problems, for the carers and those they care for, who were “excluded, socially inactive, self-harmed, taken overdose”.

“I had a nervous breakdown when my son was diagnosed. I’ve suffered with anxiety and depression ever since”

While these adverse effects and concerns were unsurprisingly the overwhelming theme of these comments, there were a few who spoke of resilience and hope in the face of such a difficult situation:

“Just makes me realise how fragile life can be and appreciate every day”

“I’m probably a stronger person as a result of it”

“Made me very determined to fight for services required and to provide best quality of life possible”
Reasons for lack of mental health support, as shown in the below chart (figure 15), most commonly relate to a feeling that this support is not needed. Of those who did not receive mental health support, only 39% cited reasons such as lack of availability of or access to services, compared to 61% who did not feel that mental health support was needed or wanted.

Mental health is clearly a significant issue, but many do not consider seeking help or believe that this help is not needed. Open discussion of mental health issues and available help is important to resolving this. To contribute to this, respondents suggest that ALD Life could:

- Connect people to local mental health authorities
- Provide counselling services specific to rare diseases; or direct people to these services
- Continue to provide information and organise Weekend events

Many spoke of the need to be “able to pick up the phone and talk to someone who understands”, a service which ALD Life already provides through our support line. In some cases, this was a recognition of work ALD Life is already doing. For others, who later reported never having used ALD Life telephone support, the issue may be awareness of the support we can offer. Others, however, suggest a need for “nurses trained in psychological support” in a similar set up to Macmillan Cancer Support. Historically, resource limitations make this difficult for ALD Life but we recognise the importance of this to beneficiaries and continue to explore options.

In response to these findings, ALD Life should increase efforts to encourage those who may be struggling with these issues to feel able to seek medical advice or counselling, by discussing available options and providing reassurance to reduce stigma.
Our survey has revealed both those with ALD/AMN and their family members are coping with mental health issues but may not be seeking support. One comments:

“I am dealing with grief every day... I am ok but I know many people in a similar situation take anti-depressants and carers in general are known to be at greater risk of dementia and depression”.

Studies have shown this to be the case in terms of depression in carers, with one suggesting almost 50% of carers faced periods of depression of at least a month. This was much higher than rates of depression in the general population (C. G. Ballard et al, ‘A follow up study of depression in the carers of dementia sufferers’, British Medical Journal, vol. 312, (1996)).

While we have identified that this is an issue which needs to be addressed, as well as gathering suggestions on how to do so, this survey has not collected information on:

- The effect of ALD Life support on mental health of those with ALD/AMN or carers of those with ALD/AMN
- Numerical rating of an individual’s mental health with or without ALD Life support, in order to compare this with information in future surveys

Future projects and surveys will seek answers to these questions in order to begin to understand how ALD Life is helping people in this area.
Searching the internet was found to be the most common way that our respondents found ALD Life, as shown in figure 16. 28% of respondents were directed to ALD Life through friends and family, a percentage of which will also have found ALD Life by Google search.

Interestingly, those who have contacted ALD Life more recently have an even greater tendency to find ALD Life through the internet: Google search, friend or family referral or Facebook/Twitter were the only options chosen by those who contacted us within the last 2 years (see figure 17, below). Just 14% of respondents were referred by healthcare professionals; none of these found ALD Life within the past 2 years.
This finding highlights maintenance of our website and social media as an important priority for attracting people to the organisation.

The ALD Life website was the most common of the ALD Life services used by survey respondents (91% have used the website, with 40% having done so in the past year, see figure 18, below). Support by email, through our information leaflets and at the Community Weekend had also been used by most respondents. While services such as grants, home visits and advocacy had not been used by over 90% of respondents, the percentage of respondents who were not aware of these services was also low (14% were not aware that ALD Life provides advocacy services; this was the highest figure, as marked in figure 18, below).

Just 3 respondents have received a grant from ALD Life, either for travel, Bone Marrow Transplant or Bereavement. These grants “helped when finances were tight.”
Respondents were asked if they had received support from ALD Life which was not covered by the options in figure 18 (above). This question revealed the importance of tailored support, with one respondent telling of support received in the form of translation of information in case of emergency whilst on holiday.

“Help in fighting legal battle for son’s carers to be injection trained”

“Helped immeasurably by way of information, emotional support and building hope (both indirectly and directly), and providing a platform to connect to others with ALD/AMN”

“A rowan tree was sent shortly after my son’s death which gives me a lot of joy”
Figure 18 has shown that respondents are aware of and using the services that ALD Life offers. The following chart, figure 19, shows the high opinions of these services, regarded almost unanimously as relevant, professional and high quality (‘N/A’ responses to this question, where the respondent has not contacted ALD Life, have been removed).

2% of respondents (1 person) has stated that ALD Life services are not professional. This is likely to have been a mistake: the respondent answered ‘N/A’ to the questions of relevance and quality, and on two separate occasions in survey comments describes ALD Life as “very professional.”

Other comments on ALD Life support included:

“Excellent charity – very professional and outward reaching, actively seeking to improve their service and push ALD up the agenda in the medical world”

“They are amazing people who, because of their own experience are always there to help”

“Brilliant at a very difficult time”
The ALD Life Community Weekend is a popular and well attended event, which consistently receives highly positive feedback. This is shown most recently by the ALD Life Community Weekend 2018 survey and report.

While the Weekend surveys provide an insight into the opinions of attendees, the Impact Survey hoped to establish why some choose not to attend these events. When asked if they would consider attending a Community Weekend in future, 57% said Yes, as shown in figure 20, below. Only 4% of respondents decided that, having attended previously, they would not consider attending a future event. In both of these 2 cases, deteriorating health was the primary reason given.

Reasons for not attending Community Weekends include health concerns and the travel difficulties these can cause. Fear that meeting others with the condition will be difficult and distressing for those with early symptoms is an important consideration for some respondents.

Those who have attended Community Weekends in the past left overwhelmingly positive feedback about the events:

“The Community Weekend is an excellent source of support and information”

“Excellent medical talks and great to make contact with other families”

“It’s a humbling yet inspiring experience to meet with other patients and their families”
The only criticism of the event was to say that presentations are “sometimes too scientific to comprehend”, an issue which was raised at the Weekend and which we hope to resolve for the next event.
IMPRESSIONS OF ALD LIFE

ALD Life hope to provide support that is accessible, valuable and appropriate to all who come to us for help. The below table (figure 21) shows the qualities we hope to achieve and how far our survey respondents agree that we are meeting these. ‘N/A’ answers have been removed.

For most of our list, over 90% of respondents agreed with the statement given:

<table>
<thead>
<tr>
<th></th>
<th>% ‘Agree’ or ‘Strongly Agree’</th>
<th>% ‘Disagree’ or ‘Strongly Disagree’</th>
<th>% Neither</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make me feel less isolated</td>
<td>97%</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Help me to feel better informed about ALD/AMN</td>
<td>95%</td>
<td>0%</td>
<td>5%</td>
</tr>
<tr>
<td>Communicate sensitively</td>
<td>94%</td>
<td>0%</td>
<td>6%</td>
</tr>
<tr>
<td>Are easy to find</td>
<td>94%</td>
<td>2%</td>
<td>4%</td>
</tr>
<tr>
<td>Are reliable</td>
<td>92%</td>
<td>2%</td>
<td>6%</td>
</tr>
<tr>
<td>Provide the best information and support for my condition</td>
<td>90%</td>
<td>0%</td>
<td>10%</td>
</tr>
<tr>
<td>Are easy to contact</td>
<td>90%</td>
<td>2%</td>
<td>8%</td>
</tr>
<tr>
<td>Provide services that are useful to me</td>
<td>82%</td>
<td>0%</td>
<td>18%</td>
</tr>
<tr>
<td>Help me to cope with my/my loved one’s ALD/AMN</td>
<td>77%</td>
<td>0%</td>
<td>23%</td>
</tr>
<tr>
<td>Spend donors’ money wisely and effectively</td>
<td>72%</td>
<td>0%</td>
<td>28%</td>
</tr>
<tr>
<td>Help me prepare to discuss my condition with doctors</td>
<td>59%</td>
<td>3%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Figure 21: Table showing how far respondents agree to statements about ALD Life

Other descriptions of ALD Life were suggested in comments:

“First class. I cannot find any fault in their ability to help and understand the trauma of a diagnosis of X-ALD”

“Professional and proactive”

“Very sensitive, supportive, patient and understanding”
Finally, respondents were asked for an overall rating of ALD Life, ranging from 0-5 (figure 22). A 0 would indicate that the respondent was Very Unhappy or had not received support, while a 5 would indicate that the respondent was Very Happy.

Both respondents giving a 0 rating explained that they had not received support from ALD Life.

Those rating ALD Life 2/5 called for an increased focus on female carriers with symptoms, while complimenting our work with affected boys: “I think ALD Life is doing a wonderful, fabulous job for families but possibly not for ladies who are alone and seriously affected”.

83% of respondents rated ALD Life either 4 or 5 out of 5 (when only UK respondents are considered this is very similar, at 86%).

The below graph (figure 23) shows these ratings in relation to when respondents first contacted ALD Life. All of those who first contacted ALD Life within the last 2 years gave a rating of 3 or above.

Reasons for these positive ratings include:

“I have never been let down by ALD Life”

“Anything I have asked, ALD Life have been really helpful with”

“These people know the condition better than anyone”
In this section and previous sections, respondents left comments on how the support they receive could be improved. Suggestions included:

- Increased support for affected females
- Support in the transition from children to adult services
- Supporting unaffected siblings
- Translated information for those in non-English speaking countries (part of our 2019 strategy)
- Professional counsellors
- Increased support and awareness around adult cerebral ALD
CONCLUSIONS

The ALD Life Impact Survey 2018 was completed by those supported by ALD Life in a range of different ways, from face-to-face support to information on our website. Respondents from around the world, who may have contacted ALD Life this year or many years ago, praised the efforts of our organisation in supporting them and their families.

The support that ALD Life provides to these people was repeatedly found to have been a lifeline for people dealing with the effects of the condition in their family. Many were often unable to think of ways to improve the service offered by ALD Life, hoping only that it would continue for themselves and others. Positive findings of the survey include:

- ALD Life and medical professionals who are specialists in ALD are the most important sources of support to respondents (80%), especially those in the UK (83%)
- Support provided by ALD Life is relevant to those with ALD/AMN, high quality and professional, according to over 90% of respondents
- The level of knowledge of ALD specialists is rated more highly by those who first contacted ALD Life more recently – this suggests an improvement in this knowledge over time, driven in part by ALD Life information and awareness efforts
- According to over 90% of respondents, ALD Life helps people to feel better informed about ALD, communicate sensitively and are easy to find and contact. We are described as reliable providers of the best information and support, making people feel less isolated

The need for further action (or for continuation or development of current work) was shown in other findings; in many cases these issues are already being addressed, or are included in future strategy:

<table>
<thead>
<tr>
<th>Finding</th>
<th>Current and Planned work</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those with ALD are waiting an average of 6 years from first symptoms before being diagnosed</td>
<td>ALD Life works to raise awareness of ALD amongst medical professionals to increase accurate and timely diagnosis. A particular focus is on newborn screening and testing males with idiopathic Addison’s Disease</td>
<td>Continue with awareness raising efforts, using these results to highlight the need for improvement</td>
</tr>
<tr>
<td>Over half of respondents receive genetic counselling</td>
<td>Raising awareness of the importance of genetic</td>
<td>Enact strategy plans around genetic</td>
</tr>
<tr>
<td>Finding</td>
<td>Current and Planned work</td>
<td>Action</td>
</tr>
<tr>
<td>---------</td>
<td>--------------------------</td>
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</tr>
<tr>
<td>when they are diagnosed (58%), this is not universally high quality (67% Good or Very Good)</td>
<td>counselling and work to ensure the quality of this service have been included within future strategy</td>
<td>counselling, while monitoring the effect of the strategy on improving these areas</td>
</tr>
<tr>
<td>Although many express concerns about their own mental health and/or that of a loved one, most (61%) do not seek specific mental health support</td>
<td>Support provided by ALD Life is greatly valued by those with ALD/AMN and those who care for them. This support can relieve pressures leading to mental health concerns, but does not specifically provide mental health services or targeted signposting</td>
<td>Begin investigation into the scale of this issue amongst those with ALD/AMN and those who care for them. ALD Life will work to understand and address these issues in a targeted mental health project</td>
</tr>
<tr>
<td>Especially in recent years, most of those supported by ALD Life find us online, through social media and our website</td>
<td>ALD Life has a strong, active social media presence. We are working on long-term improvements to our website and work to keep information up to date while this is happening</td>
<td>Maintain the ALD Life website and social media and ensure that information is accurate and relevant</td>
</tr>
<tr>
<td>Awareness of the services provided by ALD Life is good: most respondents know what services are available to them should they choose to access them. Advocacy is the least well-known of these</td>
<td>Long-term improvements to our website, as above, intend to more clearly detail available services, including advocacy</td>
<td>Increase efforts to advertise advocacy work. Implement website improvements which will clearly detail available services</td>
</tr>
<tr>
<td>Some respondents’ comments ask for increased focus on research as a means of improving our services; this may indicate a need to clarify our position as a support charity rather than a research-focused organisation</td>
<td>As above, long-term website improvements will clearly detail available services, including our position on research. ALD Life works to share research trials, information and results as much as possible</td>
<td>Investigate this in further surveys to determine if this is a lack of awareness of ALD Life focus or a request for more information on trials and results</td>
</tr>
<tr>
<td>The ALD Life Community Weekend received more highly positive feedback, with reasons for not attending all related to health, travel or a reluctance to meet those whose condition is more advanced than their own</td>
<td>ALD Life have been working to improve reporting and feedback at recent Community Weekends, so have valuable data and comments to encourage further participation in future</td>
<td>Directly address reluctance to meet others in communications around the Weekend (using feedback data), to encourage this group to consider attending</td>
</tr>
<tr>
<td>Finding</td>
<td>Current and Planned work</td>
<td>Action</td>
</tr>
<tr>
<td>---------</td>
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</tbody>
</table>
| The smallest percentage (59%) of respondents agreed that ALD Life “Help me prepare to discuss my condition with doctors”. Just 3% of respondents disagreed with the statement | ALD Life offers help to those with ALD/AMN to prepare to discuss the condition with doctors, providing the individual:  
• has found ALD Life soon after diagnosis, so this help is relevant to them;  
• or has asked for this help/could feasibly benefit from it, so it is appropriate for their situation | Investigate reasons behind this low percentage. The assumption is that many respondents did not need this kind of support; this is based on the low percentage who disagreed with the statement and the lack of comments addressing the issue |  |
| Areas which respondents hope will receive more focus from ALD Life in future are female carriers with symptoms, transition from child to adult services and adult cerebral ALD | A focus on transition from child to adult services already forms part of ALD Life future strategy. Research into female carriers with symptoms is beginning to grow and is encouraged by ALD Life. Adult cerebral ALD has been recognised as a concern for a growing number of adult men with AMN | Commit to increased focus on adult cerebral ALD. Enact strategies on transition from child to adult services. Address concerns around adult cerebral ALD by increasing focus in this area – understanding issues and planning appropriate action |  |

These results will shape the future of ALD Life to ensure that we continue to provide a high standard of support to those who need it. This will also be affected by feedback received by other means, as we actively encourage those we support to give their opinions and suggestions throughout the year.

“They are amazing people who do an amazing job...Well done ALD Life!”

“A one of a kind organisation founded by a mother whose dynamism and dedication to the cause is truly inspirational”
SURVEY FEEDBACK

Comments regarding the usability and simplicity of the survey are generally positive, with many describing it as easy to use.

Suggestions included increased focus on research and finding a cure within the survey: while ALD Life does not specifically fund research into a cure for ALD, we recognise that this is an important concern for those we support. Future questions in this area could ask about participants’ willingness to participate in research and awareness of research trials.

Questions on mental health did not ask for a numerical response, making statements about the mental health of the group difficult. This also makes comparison from one year’s survey to the next difficult. Further projects and surveys will include this question and will be compared with later results to find out how mental health is changing and how ALD Life could be affecting this.

As the most significant means of collecting feedback on our activities over the course of a year, the ALD Life Impact Survey needs to be a substantial and comprehensive questionnaire. For some, this has made the Survey longer than they would like – we have tried to combat this by limiting the number of compulsory questions. In the future, we will:

- Provide a more realistic estimate of how long the survey will take – some commenters pointed out that 15 minutes was not accurate
- Emphasise that not all questions are compulsory and that any feedback is appreciated
- Consider alternative survey platforms which allow surveys to be saved to be completed later, or which allow the survey to be submitted incomplete

The comments and feedback provided by respondents to our survey are greatly appreciated by ALD Life. They will be used to promote our work through our website, social media and other advertising, in order to raise funds and attract new beneficiaries. We will also use suggestions from the survey to improve the services we provide. The ALD Life Impact Survey 2019 will look to show our progress in these areas.

Report written by Clare Dickson, Monitoring Evaluation and Research Officer

Photos owned by ALD Life

December 2018
APPENDIX: SURVEY QUESTIONS

The questions asked are as follows.
ALD Life Impact Survey 2018

Thank you for taking part in the ALD Life Impact Survey 2018. Anyone who has a connection with ALD Life through their/their loved one’s ALD/AMN is welcome to take the survey.

Results of this survey will be used to help ALD Life to ensure that we are providing you with the best possible service to meet your needs. We want to know what we are doing well and how we could do better!

An overview of the results will be publicly available, but individual responses will remain anonymous.

Please use the comment boxes provided to give any further details on your responses.

Thanks again for taking the time to complete this survey.

* Required

1. If you are happy for ALD Life to contact you to clarify or follow up on answers provided in this survey, please leave your email address here

Survey answers will remain anonymous; your email address will be used only to clarify the answers you have given where necessary

2. ALD Life would like to use comments from this survey to improve our services and promote our work to potential donors and service users. Can we use your comments for this? *

Your comments will always remain anonymous. If you select ‘No’ to this question, we cannot use your comments.

Mark only one oval.

☐ Yes

☐ No

3. Do you have any symptoms of ALD/AMN yourself? Please choose the most accurate option for you *

Mark only one oval.

☐ I am a female with AMN, and have symptoms of this

☐ I am a female carrier with no symptoms

☐ I am a male with AMN

☐ I am a male with symptomatic ALD and Addison’s Disease

☐ I am a male with symptomatic ALD without Addison’s Disease

☐ I am a male with ALD, post-BMT, with Addison's Disease

☐ I am a male with ALD, post-BMT, without Addison's Disease

☐ I am a male with asymptomatic ALD and Addison's Disease

☐ I am a male with asymptomatic ALD without Addison's Disease

☐ I am an unaffected friend, relative or carer
4. Do you care for someone with ALD/AMN, or have you previously cared for someone with ALD/AMN? *

Please select all appropriate options: if you have lost someone to ALD/AMN, please select their phenotype and also "I have lost someone to ALD/AMN"

Check all that apply.

- I care/have cared for someone with symptomatic ALD
- I care/have cared for someone with asymptomatic ALD
- I care/have cared for someone with AMN
- I care/have cared for someone with Addison's Disease
- I care/have cared for someone who has had a Bone Marrow Transplant for ALD
- I have lost someone to ALD/AMN
- None of the above

5. Please give more details about those you care/have cared for, particularly if this is more than one person *

Please tell us how many people with ALD/AMN you care/have cared for

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6. If you are aware that someone else in your family has also completed this survey, please indicate below *

This question helps us to avoid collecting repeat information. Members of the same family are welcome to complete the survey individually to express their own opinions on their/their loved one's care.

Mark only one oval.

- Yes - more than one other family member has completed the survey
- Yes - another family member has completed the survey
- Maybe - another family member may have completed the survey
- No - no other family members have completed the survey
- Unknown

7. Location/Region *

Mark only one oval.

- Scotland
- Northern Ireland
- England
- Wales
- Europe (not UK)
- Africa
- Asia
- Australasia
- North America
- South America
8. How important are each of these in supporting you with ALD/AMN?

Mark only one oval per row.

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<thead>
<tr>
<th>Source of Support</th>
<th>1- Least important</th>
<th>2- Not very important</th>
<th>3- Somewhat important</th>
<th>4- Very important</th>
<th>5- Most important</th>
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<td>Family and Friends</td>
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<td>Lead medical professionals (ALD specialists)</td>
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<td>Other medical professionals</td>
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<td>Other</td>
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9. Comments on sources of support

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Living with ALD/AMN

10. When did you/your loved one begin to show symptoms that were later attributed to ALD/AMN?

If you are unsure, please give an estimated date. If several members of your close family have an ALD/AMN diagnosis, please enter estimated dates for each person

____________________________________________________

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11. When did you/your loved one receive a diagnosis of ALD/AMN?

As above, please estimate if unsure and answer for all affected close family members if appropriate.

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12. Were you/your loved one initially misdiagnosed?
Questions on misdiagnosis are used to discover and raise awareness of the frequency of misdiagnosis, and are not intended to accuse doctors. Information which may identify medical professionals or patients will not be published.
Mark only one oval.

☐ Yes
☐ No

13. What condition/s were you/your loved one initially misdiagnosed as having?

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14. Comments on getting a diagnosis of ALD/AMN

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15. How would you rate the overall level of knowledge about ALD and AMN by the GPs, consultants, social services, employers and education providers that you come into contact with? *
Mark only one oval per row.

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<th>Poor</th>
<th>Acceptable</th>
<th>Good</th>
<th>Very Good</th>
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<td>GPs</td>
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<td>Lead professionals (ALD specialists)</td>
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<td>Social Services</td>
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<td>Schools and Education Providers</td>
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16. What do you see as the most significant challenge or barrier facing you in relation to your ALD/AMN (or that of a loved one)?

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**Mental health support**
Coping with conditions like ALD and AMN, or caring for those with these conditions, can have negative effects on your mental health. This can lead to stress, anxiety, depression or worse. Access to appropriate mental health support and counselling can help with this. ALD Life wants to find out how important this is to you and how we can better support you in this area.
17. What effect has your ALD/AMN had on your mental health? (If you yourself have symptoms of ALD/AMN)

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18. What effect has your ALD/AMN had on the mental health of your loved ones? (If you yourself have symptoms of ALD/AMN)

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19. What effect has your loved one's ALD/AMN had on their mental health? (If you care/have cared for someone with ALD/AMN)

__________________________________________________________________________
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__________________________________________________________________________

20. What effect has your loved one's ALD/AMN had on your mental health? (If you care/have cared for someone with ALD/AMN)

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21. Comments

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22. Have you/your loved one been offered or requested mental health support, such as counselling services?

Mark only one oval.

- Offered and accepted
- Offered and refused
- Requested and received
- Requested and not received
- Not offered or requested
- Don't know

23. Do you have any comments about any mental health support you/your loved ones have received or hoped to receive?

________________________________________________________________________
________________________________________________________________________
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24. If you/your loved one has not received appropriate mental health support, what has prevented this?

Check all that apply.

- No local services or availability in these services
- Dissatisfaction with available services
- I am not aware of any available local services
- My loved one does not want mental health support
- I have never considered mental health support
- Mental health support not needed
- N/A - Support accessed
- Other: ______________________________________

25. What more could be done, by ALD Life or other services, to help you manage your/your loved one's mental health?

________________________________________________________________________
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26. Have you and/or your family ever been offered and/or received genetic counselling? *
Mark only one oval.
- Yes - genetic counselling offered and received  Skip to question 27.
- Yes - genetic counselling offered but not yet received (appointment due in the future)  Skip to question 31.
- Yes - genetic counselling offered but not yet received (NO appointment scheduled for the future)  Skip to question 31.
- Yes - genetic counselling offered but NOT accepted  Skip to question 31.
- No offer of genetic counselling received  Skip to question 31.
- Unknown - I do not know what genetic counselling is  Skip to question 31.

Genetic Counselling

27. How would you rate the quality of the genetic counselling received by you, and/or your family, prior to or after an ALD/AMN diagnosis? *
Mark only one oval.
- Very good
- Good
- Acceptable
- Poor
- Very Poor

28. Was the need to contact relatives discussed in genetic counselling conversations?
Follow-up genetic counselling involves contacting relatives of those diagnosed with a genetic condition, to discuss the need for testing for the condition and the potential risks of having children.
Mark only one oval.
- Yes
- No

29. Did the genetic counsellor offer to contact relatives you are not in touch with?
Mark only one oval.
- Yes
- No, I suggested this
- No, this was not arranged
- N/A - I am in touch with all of my relatives

30. Comments on follow-up genetic counselling for relatives

First contact with ALD Life
31. When did you first contact ALD Life?

Mark only one oval.

- This year (2018)
- Within the last 1-2 years
- Within the last 2-5 years
- 5-10 years ago
- Over 10 years ago
- I have used the ALD Life website but have not directly contacted ALD Life

32. How long after diagnosis did you first contact ALD Life?

Mark only one oval.

- Before confirmed diagnosis
- Within a few weeks
- 2-6 months
- Within a year
- 1-2 years
- Over 2 years

33. Comments on contacting ALD Life

Please tell us the reasons for any delay in contacting ALD Life (e.g. ALD Life had not been established when you received the diagnosis!)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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34. How did you find out about ALD Life?

Mark only one oval.

- Referred by health care professional
- Google search
- Media article
- Friends or family
- Facebook/Twitter
- Other:

ALD Life Support Services
35. **Which of these ALD Life services have you used?**  
*Check all that apply.*

<table>
<thead>
<tr>
<th>Used in the past year</th>
<th>Used</th>
<th>Never Used</th>
<th>May use in future</th>
<th>Was not aware</th>
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<tbody>
<tr>
<td>Email support</td>
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<td>Phone support</td>
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<td>Financial support (grants)</td>
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<tr>
<td>Attended ALD Life Community Weekend</td>
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<td>Peer support (being connected to others with ALD)</td>
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<td>Home visits</td>
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<td>Practical information leaflets</td>
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<td>Advocacy services</td>
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36. **Have you received any support from ALD Life which is not covered by the options above?**

37. **How has support from ALD Life helped you and your family?**

38. **Do you think the support you have received from ALD Life (by email, phone, face to face or through the website) is: *  
*Mark only one oval per row.*

<table>
<thead>
<tr>
<th>Relevant to you and others with ALD/AMN</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
<th>N/A</th>
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39. **Comments on support from ALD Life**

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https://docs.google.com/forms/d/1L8UYU2efznOZez6c7RMwK3I-6i7w5PLt62BYLIEdrW/edit
40. **ALD Life Community Weekend: Would you consider attending a Weekend event in the future?**
ALD Life Community Weekends bring individuals and families with ALD together to meet one another and hear from ALD experts from around the world. These events take place every 2 years and are accessible to anyone with ALD/AMN. (If you do not live in the UK, please select the final option)
Mark only one oval.

- [ ] Yes - I have attended at least one event in the past and may do so again  
  After the last question in this section, skip to question 43.
- [ ] Yes - I have never attended before but may do in future  
  After the last question in this section, skip to question 43.
- [ ] No - I have attended in the past but will not do so again  
  After the last question in this section, skip to question 42.
- [ ] No - I have never attended and do not plan to do so  
  After the last question in this section, skip to question 42.
- [ ] I need more information on the Community Weekend  
  After the last question in this section, skip to question 43.
- [ ] I have not attended an ALD Life Community Weekend because I do not live in the UK  
  After the last question in this section, skip to question 43.

41. **Comments on ALD Life Community Weekend**

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**Reasons for not attending**

42. **Please explain your response: is there a reason why you would not consider the Community Weekend in future?**

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**Grants**

43. **Have you ever received a grant from ALD Life? **
Mark only one oval.

- [ ] Yes  
  Skip to question 44.
- [ ] No  
  Skip to question 46.

**Grant feedback**
44. Grants: If you have received a grant from ALD Life, please select the type of grant received

Please select all appropriate options
Check all that apply.

- Bereavement Grant
- Treatment/Equipment Grant
- Financial Hardship Grant
- Bone Marrow Transplant Grant
- Travel Grant
- No grant received

45. If you have had a grant from ALD Life, how has it helped you and your family?

46. How far do you agree that ALD Life...

Mark only one oval per row.

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<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Not Sure</th>
<th>N/A</th>
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47. Comments on your impressions of ALD Life


48. How do you feel about the overall support given to you by ALD Life? *
Please select a number from 0-5 to indicate your rating of support given. Lower numbers indicate dissatisfaction with or lack of support, higher numbers indicate that you are happy with overall support from ALD Life
Mark only one oval.

0  1  2  3  4  5
Very Unhappy/ No Support Received  ∎  ∎  ∎  ∎  ∎  ∎  Very Happy

49. Please explain your response


50. Is there anything more ALD Life can do to better support you and your family? *


51. If you do not already receive communications from ALD Life, and would like to do so, please enter your name and email address here

See our Privacy Policy here:

Survey feedback
Thank you for completing the survey
52. Please let us know if you had any difficulties completing this survey, or have any comments on its usability