

IMPACT SURVEY 2018 REPORT SUMMARY

INTRODUCTION

The ALD Life Impact Survey 2018, distributed in September 2018, gathered the views of those supported by ALD Life from around the world. Distributed to the ALD Life network through emails, social media and eNewsletters, the survey asked questions about how individuals and families cope with ALD and AMN, and the role of ALD Life in this, in order to understand our strengths and build upon areas in need of improvement.

The survey was completed by 52 people: when considering those they care for with ALD/AMN, this was found to represent at least 95 people. This was an increase on participation in the 2016 Beneficiary Survey.

DEMOGRAPHICS

ALD Life is based in the UK but supports individuals and families around the world with ALD and AMN. This was reflected in those who responded to the survey. The number of UK-based respondents was disproportionately high; this is likely to be due to the increased opportunity for contact with ALD Life (e.g. through the ALD Life Community Weekend).

60% of respondents first contacted ALD Life over 5 years ago, with 10% having never directly contacted ALD Life (having only accessed the website). This information was collected to discover if it had an impact on impressions of ALD Life and other services.



Those responding to the survey were predominately women, either with their own symptoms (40% of total respondents) or carriers (27%). Other represented groups were men with AMN (21%) and unaffected friends, relatives or carers (12%).

Many of these care for/have cared for someone affected by ALD or AMN – almost 40% of respondents had lost someone to ALD/AMN. Respondents cared for people with AMN or symptomatic or asymptomatic ALD, some of whom had had Bone Marrow Transplants (BMTs) and/or had Addison’s Disease.

Female carrier, no symptoms	14 (27%)
Female with AMN and symptoms	21 (40%)
Male with AMN	11 (21%)
Unaffected friend, relative or carer	6 (12%)

DIAGNOSIS AND GENETIC TESTING

The average time between appearance of first symptoms and diagnosis of ALD/AMN was 6 years. 57% of respondents were initially misdiagnosed, with Multiple Sclerosis (MS) as the most common misdiagnosis among adults (children with ALD would be unlikely to be misdiagnosed with MS).

Delayed diagnosis was a source of frustration and trauma for some respondents, whilst others appreciated their luck in obtaining a prompt diagnosis. Many mentioned family history as an important factor in diagnosis, or as a missed opportunity.

Genetic counselling was offered to and received by 58% of respondents, while over a quarter of respondents had not been offered this support. 67% of those who did receive genetic counselling rated it ‘Good’ or ‘Very Good’. 80% of those who had received genetic counselling had the need to contact relatives discussed with them.

While these figures are generally encouraging, this service is not being universally offered to a high quality.

SOURCES OF SUPPORT

When asked to rate a variety of services as a source of support, ALD Life was jointly rated most important: 80% of respondents rated ALD Life ‘Very Important’ or ‘Most Important’. ALD Life specialists and lead professionals received the same ratings. This was slightly increased for UK respondents.

Lack of understanding of ALD/AMN was often given as the key reason for lack of support from other services; the ability of ALD Life to provide this informed support was a “lifeline”.

SERVICES' LEVEL OF KNOWLEDGE

The level of knowledge of ALD specialists and lead professionals was rated the most highly of all services supporting those with ALD/AMN. Efforts by ALD Life to increase awareness within the medical community and to promote connections with ALD specialists in the last 5 years can be seen to have had an effect: 0% of those who first contacted ALD Life in the past 5 years rated the level of knowledge of ALD specialists as 'Poor' or 'Very Poor'.

This compares to the level of knowledge of social services, which was rated poorly irrespective of when the respondent first contacted ALD Life. While ALD Life works with social services when providing one-to-one support and advocacy, improving the level of knowledge of social services as a whole is not a realistic aim for ALD Life.

Areas where lack of knowledge was considered to be a particular problem were transition from child to adult services and the effect of the condition on women.

MENTAL HEALTH

Many respondents raised concerns about their own mental health, or that of their loved ones, but only 30% had received mental health support. Stress, frustration, anxiety and depression were common themes.

Of those who did not receive mental health support, just 39% cited reasons relating to availability or quality of services. The remaining 61% did not consider mental health support as an important priority, despite raising concerns about it. ALD Life can contribute to open discussion to reduce stigma around mental health support; respondents also suggested that we work to connect people to local mental health authorities and either provide or direct people towards counselling services.





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

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

ALD LIFE SERVICES

Google search was the most common means of finding ALD Life. Respondents who first contacted ALD Life within the last 2 years found the organisation through Google, Facebook/Twitter or referral by family or friends. Maintenance of the ALD Life website and social media presence are shown to be highly important in attracting those with ALD/AMN to our services.

91% of respondents have used the ALD Life website for support; almost 50% of whom have done so in the past year. Email support and practical information leaflets were also popular services. Awareness of services offered by ALD Life was high: 14% were unaware that ALD Life can provide advocacy services, this was the highest figure.

Respondents agreed that ALD Life services are relevant, professional and of a high quality.

ALD LIFE COMMUNITY WEEKEND

The ALD Life Community Weekend received more positive feedback in this survey, reflecting results of the Weekend Survey earlier in 2018. Respondents were asked if they had attended previously, would consider attending in the future, and reasons for not wanting to attend.

Reasons not to consider attending in the future fell into 3 clear categories: inability for health reasons; inability for travel reasons (sometimes linked to health); and fear that meeting others with ALD/AMN will be distressing, particularly for those with early symptoms.

Comments from attendees of previous events were overwhelmingly positive, such as "It's a humbling yet inspiring experience to meet with other patients and their families".

IMPRESSIONS OF ALD LIFE

Over 90% of respondents agree that ALD Life:

- Make people feel less isolated
- Help people to feel better informed about ALD/AMN
- Communicate sensitively
- Are easy to find
- Are reliable
- Provide the best information and support for the condition
- Are easy to contact

The statement which was supported least (59%) was: 'ALD Life help me prepare to discuss my condition with doctors'. Just 3% reported that they 'Disagree' or 'Strongly Disagree' with this statement, suggesting that this support was simply not needed by a large percentage of respondents.

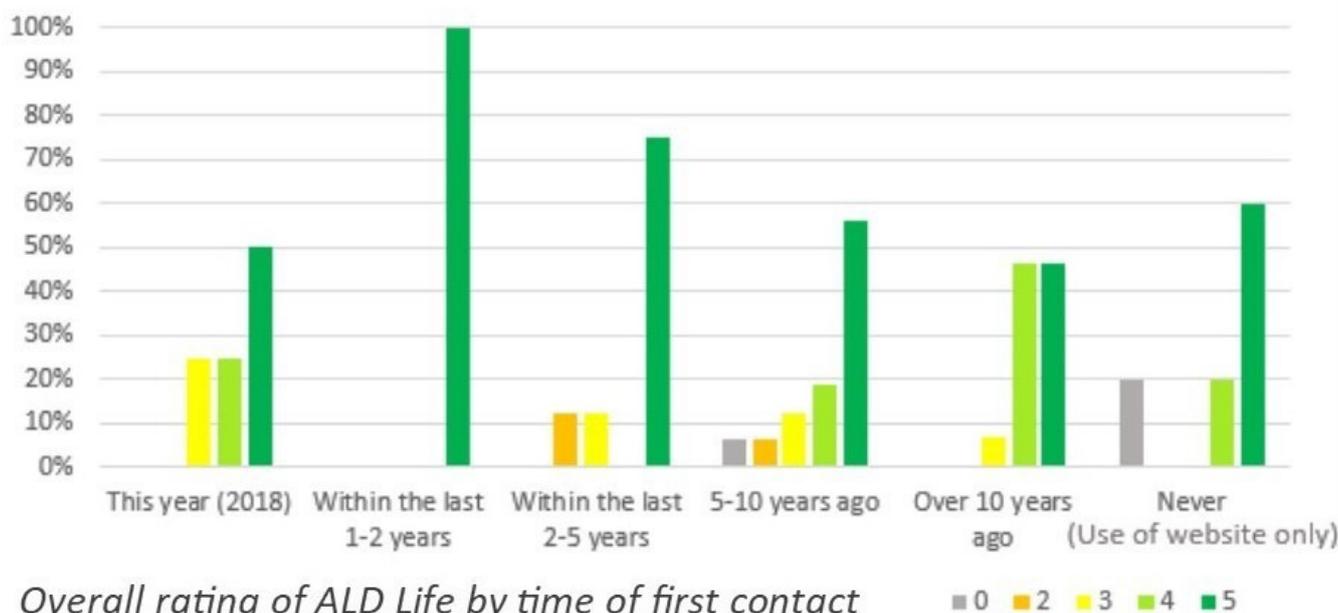
Respondents rated ALD Life from 0-5, with 83% giving a 4 or 5 rating. No respondents who have received support from ALD Life gave a 0 or 1 rating. All of those who first contacted ALD Life within the last 2 years gave a rating of 3 or above.

Suggestions for improving support included:

- Increased support for affected females
- Support in transition from children to adult services
- Supporting unaffected siblings
- Translated information for those in non-English speaking countries
- Professional counsellors
- Increased support and awareness around adult cerebral ALD

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

All of those who first contacted ALD Life within the last 2 years gave a rating of 3 or above



CONCLUSIONS

The Impact Survey 2018 has revealed significant successes for ALD Life services, with findings such as:

- 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:

FINDING:	CURRENT AND PLANNED WORK:	ACTION:
Those with ALD are waiting an average of 6 years from first symptoms before being diagnosed	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	Continue with awareness raising efforts, using these results to highlight the need for improvement
Over half of respondents receive genetic counselling when they are diagnosed (58%), this is not universally high quality (67% Good or Very Good)	Raising awareness of the importance of genetic counselling and work to ensure the quality of this service have been included within future strategy	Enact strategy plans around genetic counselling, while monitoring the effect of the strategy on improving these areas
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	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	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
Especially in recent years, most of those supported by ALD Life find us online, through social media and our website	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	Maintain the ALD Life website and social media and ensure that information is accurate and relevant
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	Long-term improvements to our website, as above, intend to more clearly detail available services, including advocacy	Increase efforts to advertise advocacy work. Implement website improvements which will clearly detail available services

FINDING:	CURRENT AND PLANNED WORK:	ACTION:
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	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	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
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	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	Directly address reluctance to meet others in communications around the Weekend (using feedback data), to encourage this group to consider attending when they feel ready to do so
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

SURVEY FEEDBACK

Feedback on the survey itself was generally positive. An important means of gathering opinions, the survey must be substantial and comprehensive, making it difficult to address comments about its length. The number of compulsory questions was limited to increase at least partial participation.

To improve the survey in the future, we will:

- Include mental health questions which ask for a numerical response, allowing for generalisations and year-on-year comparisons
- Assess beneficiary understanding of our position on research through more specific questions
- Include questions around willingness to participate in and awareness of trials
- Provide a more realistic estimate of the length of the survey
- Emphasise that questions are not compulsory to encourage those with limited time to at least partially contribute
- Consider alternative survey platforms which will allow surveys to be saved and completed later, or to be submitted when incomplete

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ALD Life December 2018