contact *For families with disabled children*

Parent Support Group Action Pack

How to spread the word about your support group
Press releases, newsletters, flyers, posters, social networking and websites

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Introduction to communications

Making good use of different communications tools, for example Facebook, or talking to the media, will help you to:

- promote your group and activities
- attract new members and
- help you to achieve your aims.

Spreading the word about your group will involve a range of activities, but you may not want or need to use all of them. Activities can includes creating press releases, talking to the media, writing a newsletter or developing an online presence.

You will find that if you have clear aims and objectives you will gain so much more you're your communications activities, and having clear messages will make it much easier for you to establish your support group. You will find lots of information and advice about developing your aims and objectives in our guide *Starting a local parent support group.*

The main thing to remember is to have a go! Whether you write a blog, set up a Facebook group or conduct an interview on local radio you will promote your group and you will soon work out which forms of communication work best for your group.

Utilising social media can me a great way to communicate – it can be quick and cheap and you may find that lots of your potential members are already online and ready to connect. Be prepared to use the medium that works best for your group of families. Effective communications may just mean making the most of what your families are already using.

You don't need to be an expert to get the most out of communications and this guide will provide you with lots of advice and information, and a selection of useful resources at the end of each section.

Your brand and house style

Decide on a brand look for your group. This can include a colour as well as a logo and a font that you consistently use. This will ensure your communications look professional and recognisable as coming from your particular support group. For more information about this see *Creating an identity* in our guide to Starting a local parent support group.

In addition, you might want to collate some 'house style' rules for your newsletters. Aspects you might want to consider include:

- how you refer to your organisation; for example, 'Contact' not 'Contact A Family' or 'CONTACT A FAMILY'
- name of your newsletter - 'AS News' or 'as news' or '*AS News*'
- titles of regular features should be kept consistent.
- layout of contact details: 'Tel. (0123) 456 789' or 'Phone 0123 456 7989'

Press releases

A press release is a short summary of an event or other piece of news. This is one of the best and easiest ways to alert the media about an event or campaign you are organising.

A press release needs to be topical. It should be made very clear what is new or what the forthcoming event is. A short, well-written, press release can save a journalist an enormous amount of time and effort. With deadlines to meet, that can mean the difference between using your item or not.

Do not completely rely on the media taking up your story. Local media can be easily diverted if a news story develops! If it is vital that your information is published make sure you have alternatives – you could produce a flyer or poster with all the necessary information and distribute, or you could use social media sites such as Facebook or Twitter to spread the word.

Once you have built up a rapport with a journalist or editor, a press release may not be appropriate or needed. A telephone call or personal visit may be more suitable. Often positive personal contact can mean the difference between a short item of news and a full length feature. What is most important is to build up a relationship with local media.

What should be in the press release?

- The title should be short, say what the press release is about and contain the keywords.
- Write a short introductory paragraph which includes the five 'Ws': What, Who, Where, When, Why. This may be the only part of the press release the editor reads so include all the main details.
- Write the most important facts at the top of the press release – editors short of space may cut from the bottom upwards.
- Include a quotation to make the press release more personal, for example: Sue Clarke, group co-ordinator, said: "We provide support for families in the local area – a place to meet, share experiences and reduce feelings of isolation."
- Give the contact details for the group which you want the paper to include in the article.

- A note to editors at the end of the press release giving them brief details about the group.
- Write the date at the top of the press release.
- The name and telephone number (day and evening) of someone who can be contacted for further details.
- Try not to include jargon or abbreviations.

Tips on writing a press release

- Find out when press deadlines are.
- Decide who you want to target: families only or professionals as well? People from which geographical area? – this helps you decide which publications to send it to.
- You should aim to use just one side of A4 – certainly no more than 300 words.
- No sentence should be longer than 20 words.
- No paragraph should be longer than six sentences.
- Write as factually as possible. It is a journalist's job to think of an 'angle' for the story.
- Stick to a single topic. Don't be tempted to include information on future events.

Different types of press

- Tabloid newspapers tend to go for the interest story format with headlines such as 'My daughter is the only one in the UK with A N Other Syndrome'. The bulk of the story will be about the girl and her family. These stories are usually written internally. It can be difficult to ensure accuracy and the inclusion of your group details.
- Broadsheet newspapers give prominence to research findings such as 'One in every 30,000 children is thought to have mild A N Other Syndrome'. The text will cover the background and implications of the research with a short quote from a family. You are more likely to be able to work with broadsheet journalists to ensure accuracy and correct details of your group.
- Local papers like stories of local interest e.g. local schools, families, events etc.
- Trade press and magazines – focus on specific areas, hobbies, jobs etc. Bear in mind magazines have a much longer lead time than daily newspapers so check print deadlines early, you may need to send something out months before your event

Sending your press release

Before you send your press release:

- make sure the press release is agreed by all who need to see it.
- check you have permission to use any quotes.
- double check dates, times and contact details.
- inform any interested parties, for example, doctors or other professionals and families mentioned, about the release before you send it to journalists.

Who should you send it to?

- Read the papers, watch the television programmes and listen to the radio shows you are considering and get a feel for them: would they be interested in your story?
- Phone or do an online search of the papers, television or radio station and ask for the name and email address of the most appropriate journalist to send your release to.

How should you send your press release?

Email: put a brief but interesting title in the subject line that summarises the story. Include the press release in the body of the message, not as an attachment. Follow up with a phone call.

Always follow up with a phone call to check that the press release has been received and see if they have any questions or would like more information.

Should you include a photograph?

Local newspapers are always looking for good photographs. If you are holding an event which is a good photo opportunity, you should contact your local paper and ask if there is a photographer available to attend.

If there is no photographer available, you could try taking a picture yourself and sending it to the newspaper. It's worth remembering that newspapers are not keen on photographs of cheque presentations or people standing in a long line. Group photographs of children or families or people taking part in an activity are more likely to be included.

You could send a photograph with your press release. Alternatively, you could include a note at the top of your release – photographs available on request. This is particularly relevant if you are sending the release out by email as attaching large photographs may prevent your email from being delivered.

If you do include a photograph with your release, make sure that you have permission from the families in the photograph to use the photograph in this way. Permission is discussed in more detail in the Group Action Pack Guide *Holding a Family Day.*

What does 'embargoed' mean?

Some press releases are embargoed. If you want to publish research on a particular day to make a big impact or you want to publicise an event on the day it happens, you can use an embargo. This means the publication cannot print the information in the release until after a specified time and date (see example press release below).

There are further examples of how to write a press release in the links at the end of this pack.

Example of a press release

Contact: Elaine Bennett, Media Officer, to: 020 7608 8700
        e: elaine.bennett@contact.org.uk

For immediate release, 9 February 2018

STOP CUTS TO VITAL SERVICES FOR DISABLED CHILDREN SAYS LOCAL GROUP

Local parents in Cornwall are joining forces with other families up and down the country to put pressure on all local authorities to stop cutting vital specialist services for disabled children and their families.

The parents', who are supported by disability charity Contact, want local authorities to recognise that long waiting times and cuts to essential services are unacceptable and may be harmful to a disabled child's health and development. Services like speech and language therapy, school transport and short breaks are all affected.

The families want local authorities to do more to ensure they are at the heart of local planning, decisions and commissioning of services and forms part of Contact's *Cuts Watch* campaign to find out more about where and what services are being cut and their impact.

Mrs Jones from Cornwall represents parent-carers in the area. She has a seven-year-old son, John, who has cerebral palsy and says: "It's time for local authorities across the UK to put an end to cutting services for disabled children and their families and to do more to prioritise their needs. When a disabled child gets the right support they thrive. When these services are reduced or cut altogether, their condition can get worse or they can struggle to learn crucial independence skills such as walking and talking.

"As a mother of a disabled child I want to make sure that no child has to wait months or years for an appointment with a specialist or to get a diagnosis for their child. It's vital that as a group we have more say in how our local councils and health services run and deliver services so that

delays in accessing speech and language and occupational therapy or mental health support for example is no longer the norm for families with a disabled child."

Una Summerson from UK charity Contact says: "Cuts and pressures on local authority and health budgets over the last few years are chipping away at the vital services for families with disabled children that enable them to take part in everyday activities, keeping them working and staying healthy. While Contact recognises that local councils have a difficult decision to make, we fully support local parent groups who are challenging local decisions to cut funding for children's services such as short breaks, school transport and speech and language services."

Notes for editors

- **Information about the parent group / forum goes here**
- **Contact details for more information about this press release goes here**
- Contact supports families with disabled children across the UK. Whatever the condition, whenever they need us, wherever they are. We provide information, advice and support and campaign to improve their circumstances, and for their right to be included and equal in society.
- For more information about Contact and the Cuts Watch campaign contact the charity's press office: press@contact.org.uk or call 020 7608 ****

Ends

Talking to the Media

Talking to the media about your support group and about your child's condition provides an opportunity to:

- raise awareness of the work you do
- reach out to more parents
- raise awareness of a condition
- raise the profile of your group with potential funders, policy makers and other related organisations.

Being interviewed by a journalist

A major reason for you agreeing to an interview will be to raise awareness of the support group. The media are most interested in human interest stories and will probably want a personal angle to the story. It is advisable to consider how much you want to reveal about your family situation and your child's condition before the interview.

Remember you are in control and are within your rights to ask what sort of article it is that your interview will be a part of. What will be the central theme of the article? Be aware that you can withdraw at any time if you are unhappy with the journalist or the article.

Journalists are often in a rush and can sometimes get facts and figures incorrect. It's worth checking details with them, such as telephone numbers, addresses and spelling of names.

You can ask the journalist to provide a list of questions so that you can prepare. You can also ask the journalist to read back the transcript so that facts can be verified. It is not always possible to see the article before it goes to print, but certainly you can insist on having a good understanding of what the piece will contain.

If the journalist asks you a question that you are not happy about or which you don't feel confident enough to reply to, it is perfectly ok to say so.

Remember to ask when the article is due to appear so that the group can prepare for possible public interest and increased enquiries.

TV and radio interviews

Check the context your interview will be used in. What is the programme about? What is the purpose of your interview? How will your child and family be portrayed?

Before the interview, think of three points you would really like to get across and stick closely to this. Using examples, imagery or some basic statistical facts will make more interesting listening. Before the interview starts, ask what the first question will be and how long the interview will last. You will want to know whether it is 'live' or recorded. 'Live' has the advantage of broadcasting exactly what you have said. Recorded material will probably be cut and edited, but you have the advantage of being able to stop and ask to rephrase your answer.

Local stations may be interested in support group events for inclusion in features such as 'What's on' slots, news bulletins, longer features or as part of a social action/community programme.

If you are asked to take part in an interview, think about the following:

- consider what key messages you want to get across to the listening public
- try to brief the interviewer first. They should at least know your name, the name of your group and the main information you want to get across.
- be ready with some facts about the group and your topic, but bear in mind that most interviews are very short – get your key information in early.

National radio and television include more factual programmes and important news interest stories.

- Try to ensure that details of your group are given at the end of a programme.
- Unless you are fully prepared for it, avoid your telephone number being given at the end of the programme (your phone line could be completely blocked with calls – some made in the middle of the night!).

If you do speak to the media, it would be great if you could mention Contact as well as details for your support group.

Useful Contacts

How to get local media coverage – a press kit for Locality members
This guide aims to help community and voluntary organisations approach local media.
http://locality.org.uk/resources/press-toolkit/

KnowHowNonProfit
You'll find lots of useful information on media, marketing and communications on NCVO's KnowHowNonProfit website
http://knowhownonprofit.org/campaigns

***Making the Media Work for You* - European Journalism Centre**
This new resource published by the European Journalism Centre is aimed at civil society organisation communicators. Whether you're running local or national support group, the Guide has practical, cost-effective strategies to help you raise and maintain your visibility and impact.
http://mediapusher.eu/pressfreedom/downloads/making.the.media.work.for.you-ebook.pdf

Skills Guide: How to write a press release'

Who? Communications has an online guide to getting your message into the media. The guide goes through the process of writing a press release, deciding when to use a press release rather than social media, who to target and how to produce it.
www.whocommunications.co.uk/WhoComms-write-a-press-release.pdf

Newsletters

As well as working with the media you will also want to find other ways to tell people who you are, where to find you and what support you are offering. Below you will find information and tips to help you produce leaflets, posters and newsletters.

A newsletter is a valuable tool for parent support groups. Newsletters are also a useful way to share information about the group with professionals and fundraisers. A good newsletter accompanying a fundraising request can be very persuasive. How often you produce a newsletter will depend on what you wish to communicate and how much time or budget you have. It is better to produce a good-quality newsletter less frequently, rather than a more frequent but less useful publication.

The format of a newsletter can range from an emailed letter with hyperlinks and images to an emailed PDF, an A4 photocopied sheet, or a typeset commercially printed version that is distributed by post. However you chose to publish, always remember it's the content that matters.

Print vs online newsletters

Whether you chose to distribute printed newsletters or send your publication electronically there are pros and cons. It is worth considering that the best option is often a combination of both. A printed newsletter could be sent once or twice a year and more regular communication could be sent via an online/ email version.

A few things to consider when deciding which option is best for you:

- **Cost**
  Bear in mind that printing newsletters can be costly, even photocopied versions incur the cost of toner cartridges, art paper (for a more professional look) and distribution costs. If you chose to distribute by email you can save on postage and printing costs and time. This makes it a cheaper, quicker way of staying in touch with your members which is particularly useful if you wish to contact them more regularly.

- **Format**
  A printed or photocopied newsletter can be well designed and often generates a higher response rate than emailed documents. However, an emailed newsletter doesn't simply have to be an online version of the printed one. If you wish to send a regular newsletter it can be in the format of a fun, informative email that includes links to websites, email addresses, quizzes etc thereby encouraging your community to engage with you. Email communication can be much more interactive than printed.

- **Distribution**
  If you chose to send your newsletter by email you must ensure that all addresses you use comply with the most up to date GDPR (General Data Protection Regulations) rules .You also need to ensure that each and every version you send out has an 'unsubscribe option'. The Information Commissioner's Office has a full guide to GDPR and links to useful resources.

  https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/

  Bear in mind that sending out a newsletter as an email attachment to a large number of addresses can be problematic. Large attachments or emails sent to several email addresses are likely to be blocked as SPAM and never get read by your members so consider sending them in smaller amounts, to checked email addresses and without attachments.

  Not everyone has an email address or internet access – if you chose e-newsletters, you may also need to print off a couple of copies to send by post.

  If you are sending printed newsletters you need to consider the cost of postage within your budget.

Getting the content right

Whichever type of newsletter you chose, content is key. Consider the purpose of your publication before writing the content so you make sure you include what is necessary. Do you need to include information, relationship building activities like quizzes or feedback, fundraising ideas etc?

It should be broad enough to interest the majority of the group. Parent support group newsletters often aim for an informal tone. You might want to include personal articles, professionals' input, news items, feedback from families, details of play schemes, other events and useful tips for parents.

When you are writing about a complex issue, aim to present a balanced and unbiased view point. An explanation should be provided for any complex terms.

Contributions should be encouraged from across the group and your contacts. No one person should be responsible for writing all the articles. You can include a wide range of contributors; professionals, families, charities, local organisations etc. There will inevitably be views expressed which are personal to the writers so you must include a disclaimer phrase in every issue (see page 5 for information on disclaimers).

A newsletter is one of the best publicity materials your group has. Include contact details for the group. If someone who has never heard of your group picks up your newsletter, will they be able to tell what the group is all about?

If you are a national rare condition support group, you might want to include medical information. Sources of medical information include:

- articles from medical journals
- the internet (Contact has an article on finding online medical information - https://www.contact.org.uk/advice-and-support/medical-information/finding-medical-information/
- your group's medical advisor
- Contact's online medical information (please acknowledge source).

Be open to feedback and encourage comments. For evaluation of your newsletter's success, consider:

- how well informed your supporters are
- how much comment about group activities you receive from outsiders
- whether take-up of services or attendance at events highlighted in your newsletter has increased.

Layout and design

The aim should be to produce as attractive, clear and 'reader-friendly' a publication as you can. Be ready to respond to feedback and review and change the layout of the newsletter in its early days. A clear brand for your organisation, including a colour, distinctive graphics, logo and font style will help.

A computer with a desktop publishing programme (DTP) can make this job easier by enabling you to move the text, logos and images around on the screen, but many groups have made very effective leaflets with a simple word processing package. Many local adult education programmes now include desktop publishing courses. Contact your local council or adult education centre for details.

Don't be afraid to ask friends, family or local contacts for artistic help with logos, illustrations or graphics and consider whether anyone within your group who has access to a computer for word processing and DTP would be willing to help. If you are asking local companies for help it is worth giving them the opportunity to put their logo/ branding or company information at the end of the newsletter so they benefit from the advertising in return for their support.

Tips to make your publication look attractive

- Don't try to squeeze too much on a page. A bit of 'breathing space' makes the page look attractive and easier to read.
- Use a clear font, such as Arial or Trebuchet MS, and a reasonable font size, for example 12 or 14 points.
- Don't use more than one or two fonts and styles.
- Depending on format, use columns – but vary layout for particular features.
- Avoid using all CAPITALS as they are more difficult to read and can appear as 'shouty'.
- Use bold text for headings rather than <u>underlining</u>, which can be difficult to read.
- Use left-aligned text and avoid using justified text where both sides of the text is aligned. This is difficult to read and can introduce ugly spacing between words.
- Add variety and visual appeal to your pages. Break up heavy chunks of text by including photographs (see below), pull quotes (quotes from the text repeated in a larger point size), and boxes.
- Use real photos rather than clipart.
- Always get someone who hasn't been directly involved in writing the material to proofread.

Using photographs

Take photos whenever your group has an activity.

NB Everyone in the shot **must** give their permission for the photograph to be used in any way. Prepare a permission form for them to sign – remember to allow for use online as well as in printed materials. Your group can then build up a library of photographs. Try to use clear positive images wherever possible.

There are many examples of photo permission forms available online. Contact has a photo and film permission form that groups can adapt, you will find a copy in our *Holding a Family Day* guide.

Photographs should be high resolution to ensure good enough quality print. The higher an image's resolution, the more detailed and crisp it will appear on a printed page. Resolution refers to the dots of ink or electronic pixels that make up a picture whether it is printed on paper or displayed on-screen.

The terms DPI (dots per inch) or PPI (pixels per inch) may be familiar if you've used a scanner or a digital camera. DPI and PPI are measures of resolution. Images usually need to be a minimum of 300 DPI or PPI for use in print and are usually a jpg file. For best results photographs should be more than 1MB (mega bite) in size.

Disclaimers

You should include a disclaimer either on the front or at the back of your newsletter. This provides an element of protection against anyone misunderstanding or misusing the information in your newsletter. There may also be a delay between your newsletter going to print and being posted so some information may have changed during that time, for example, dates of events or deadlines for consultations.

Examples of disclaimers

- The views and suggestions in this newsletter are those of individual contributors and are not necessarily supported by XXX Group. XXX Group cannot accept responsibility for any goods or services mentioned in or enclosed with this newsletter/magazine.
- Great care and attention has been given to the compilation and preparation of this newsletter to ensure accuracy, XXX Group cannot take any responsibility for any errors or omissions. All information was accurate at the time of going to print. The views expressed in this newsletter are for information purposes only and are in no way intended to replace medical care and attention.
- The management committee of the [inset the name of your group] do not necessarily agree with the views, activities or actions expressed in this newsletter nor do they recommend any particular methods of treatment. Any new treatment must never be started, or existing treatment changed, without first consulting your doctor.
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Your management committee should agree on the wording it wishes to use and there are many more examples available online.

Checklist of vital information

- If you are a registered charity, your number must be on every printed item.
- If you are registered company, include your VAT number.
- Ensure all telephone numbers and other contact details are correct and current.
- Check that any links to websites work.
- Check that all contributors are credited with names spelt correctly.
- Check all photos have full permissions, are captioned and credited.
- Check you have included disclaimer statements.

Production of your newsletter

E-newsletter production

If you are producing an e-newsletter there are online tools and templates which you can use to help you. Some of these services are free and others make a small monthly charge. Some will manage your email list for you and produce a report about the newsletter you have sent out. These reports provide information about the newsletter; for example, how many were opened and which of the links your readers clicked. This information can be used to help you develop your newsletter and ensure you provide news and information that your readers will be interested in.

Here are some suggestions but there are many others available online. Do shop around to find the best one for you and tell them you are a parent support group and a charity if they are charging for their service.

www.mailchimp.com
www.newzapp.co.uk
www.constantcontact.com

Printed newsletter production

If you are going to print your newsletter, you need to decide how many you need, (known as a 'print run'). Consider the numbers of families, likely new members and interested professionals you wish to reach. Other voluntary organisations may want copies. Newsletters are also useful publicity to send to libraries, children's centres and other places families are likely to go. Other budget considerations if you print your newsletter are:

- will the newsletter be free to members and supporters?
- will you charge for some members, for example, extended families, professionals and other interested people?
- will you take advertising?

With regard to printing or creating the newsletter consider whether anyone within your group has access to photocopying or printing facilities and stationery supplies to keep your costs down.

If you are going to use commercial printers be aware that prices can vary greatly. Make the companies aware you are a parent support group and a charity and ensure they understand you need a competitive price. Ask the printer to show you samples of their work. It is worth asking whether they will donate their print services in return for recognition at the base of the newsletter.

Obtain several quotes (a minimum of three). If you feel more confident with a pricier printer don't be shy about asking them to match a lower quote.

The printer will need to know the format, extent (number of pages), quality of paper, type of cover, and quantity of each print run. Also depending on the print run and type of printing, the number of colours (whether you go for one, two or full colour) also affect the price. They will also advise how you should supply the electronic PDF file to them.

Depending on how many copies you are planning to distribute, economies of scale may mean that it is cheaper to print above a certain amount rather than photocopy.

Production schedules

Do not be too tough on yourself. Compiling the newsletter will probably take longer than you imagine. Allow plenty of time to gather a full range of articles and to check sources. Plan volunteer help in advance and make sure everyone is clear on the schedule. Prioritise the articles – some may be more appropriate for future editions. Make sure that any events publicised will not be over before your newsletter reaches your readers.

If you are printing the newsletter, discuss with your printer how long they will need to produce the finished copies and try to ensure that all parties stick to the agreed deadlines.

Include the deadline date for contributions for the *next* newsletter in every issue – make it clear where to send contributions and any criteria such as length of article, format etc.

Planning a leaflet

Leaflets to publicise your group and your events should be simple and accurate. Remember that too much text can be difficult for the reader to take in. You might consider having a range of leaflets for different purposes:

1. An introductory leaflet for parents which would contain:

   - the group's aims and main activities
   - a contact name and address and/or
   - telephone number.

2. If you are a national rare condition support groups you might want to create a leaflet giving:

   - information on the condition and any alternative names
   - inheritance patterns (if appropriate)
   - pre-natal diagnosis (if appropriate)

3. As the group grows you may decide to produce leaflets on a range of subjects, which may include:
   - education
   - information for siblings
   - information for teachers and other appropriate professionals

Consider the format that will best suit the amount of information you want to include. You may also wish to include a form to request further information as a tear off section of the leaflet.

Planning a flyer or poster

Flyers and posters are a good way of publicising the group and for advertising specific events. Do not put too much information on a poster – keep it very simple. Remember to include all the information:

- what the event is
- who the event is for
- date, time, place, any cost
- contact details
- any additional information, such as whether there is a crèche, accessibility information.

Consider size — A4 is ideal to fit on notice boards. Ensure that images and key text are large enough to be readable from across a room.

You can also produce eye-catching posters, which include enough blank space to add event details in marker pen or by putting them through a photocopier.

Possible locations for posters include:

- clinics
- children's centres
- libraries
- supermarket community noticeboards

Distribution ideas

Make the most of your leaflets, posters and newsletters by distributing them where they will be most useful. If you are clear about who your group is aiming to reach, it helps you identify who your useful contacts will be. For instance:

- parents whose children are deaf or have impaired hearing: useful contacts – ENT specialists, audiologists, speech therapists, educational support services, peripatetic teachers, National Deaf Children's Society

- parents whose children have a learning disability: useful contacts – child development team, portage workers, community paediatrician, educational psychologist, opportunity playgroup, other national charities such as Mencap and local charities

- parents whose children have specific, rare conditions: useful contacts – specialists with an interest in the condition, specialist centres or clinics, charities or groups who support rare conditions

- parents in your local area regardless of their disability: useful contacts – schools, GPs' surgeries, local shop noticeboards, libraries, local family information services, and if you are in England, your local parent carer forum.

Useful contacts

Charity newsletter design tips
http://www.flyingkite.co.uk/charity-newsletter-design-tips/

CharityComms
The CharityComms website has information and resources on producing publications, publicity and more.
www.charitycomms.org.uk/articles

How to write an E-newsletter – KnowHowNonProfit
An online guide to key steps for writing effective marketing emails. This guide focuses mainly on producing good copy rather than using technology.
http://knowhownonprofit.org/how-to/how-to-write-an-e-newsletter

The Media Trust
A range of media information, services and training for not-for-profit organisations. Their Community Newswire service helps charities, communities and citizen journalists get their stories into the national and regional media.
www.mediatrust.org

Reading between the lines: Trends in Charity Magazines and Newsletters in the Digital Age
This free report looks at what's happening in the voluntary sector around digital and print magazines and newsletters and compares that to changes in the commercial and public sectors.
www.charitycomms.org.uk/articles/charity-magazines-has-print-had-its-day-our-latest-free-report

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Introduction to social media

Being a parent of a disabled child can sometimes be an isolating experience. Support groups provide a great place to meet others who are going through similar situations. It is not always practical for parents to meet in person, especially for national rare condition support groups. Many local and national support groups use social media to raise awareness of their activities and to campaign on issues they care about.
This section of the guide will explain what social media is, how you, as a parent, carer or support group leader, can use it to connect with others, and will give you ideas on how this can help your support group.

How can social media help support groups?

The rapid growth of social media in recent years has several benefits for support groups:

- it is a low-cost way of sharing information
- existing 'real-life' networks can be enhanced
- you can gain an awareness of the needs and interests of your members as they share thoughts and ideas
- it can be a great alternative for parents who struggle to use conventional support channels because of access issues, financial constraints or fears of social exclusion.

What form of social media is best for my support group?

Before you start a social media account for your support group, consider a few simple questions:

- Who is your audience?
- What do you want to communicate – news, information, personal stories?
- Do you have the time to maintain and monitor your social media?

> Find out what social media sites your members are using already. It will be far easier to get them to engage with you through a site they are already familiar with, rather than trying to get them to sign up to something completely new.

Examples of social media sites you might use

facebook.

Allows users to create and customise a profile with photos, videos, and information about themselves. Users can then communicate with friends and keep up-to-date with all their friends' interactions through Facebook's 'News Feed'.

It is incredibly popular and used by a wide array of people. It is a great means of facilitating an interactive community. You can set up a page or a group to share information, news and resources, and also to foster discussion.

You can also set up a closed group where members have to join. This can be a good way of creating a supportive online community and can encourage parents to share experiences.

You can find more information about the difference between Facebook pages and groups here: https://www.facebook.com/help/155275634539412

twitter

Enables users to send and read messages known as 'tweets'. Tweets are text-based posts of up to 140 characters displayed on the author's profile page and visible to the author's 'followers'.

Twitter is a good means of pushing out short messages quickly, and for brief interactions with others. It is easily used on mobile phones. There is plenty of scope for making connections with others, be it other charities, MPs and celebrities.

You can find a brief introduction to making the most of Twitter here:
https://support.twitter.com/categories/281

Blogs

Short for 'Web logs', are online journals. People can also link their blogs to other websites and blog posts, and allow readers to comment on the original post, which enables ongoing discussions. Blogs are a good way of getting longer pieces of writing out into the wider world. The 'comments' function can help start discussion and foster a community. To save time, your group could even have a blog site instead of creating and updating a website. There are several sites where you can set up blogs for free. Two of the most popular are wordpress.com and www.blogger.com/

If you choose Wordpress and decide later on to move to an externally hosted website, Wordpress make this relatively easy.

You Tube

Is a website on which users can upload and share videos. It is ideal if you have any budding film-makers in your midst. You may find a new audience, or reach people who are less comfortable using social media. Video is an incredibly powerful means of communicating your story.
www.youtube.com

Instagram

Instagram allows you to build a visual identity by sharing photos and videos.This can be a good way of reaching a younger audience as 50% of users are under 30.
https://www.instagram.com/

What's App

WhatsApp Messenger is a freeware, cross-platform messaging and Voice over IP service owned by Facebook. It allows users to send text messages and voice messages, make voice and video calls, and share images, documents, user locations, and other media. This could be useful for keeping in touch with small groups – e.g. the committee keeping in touch for updates rather than always having to have face to face meetings.
https://www.whatsapp.com/

Safety on the internet

The internet is a central part of many people's lives. It has opened up new opportunities for research, entertainment, campaigning and communication amongst friends and like-minded people. However, just as in the 'real world', it pays to take care. Be careful with people you do not know, just as you would be when meeting someone for the first time face-to face. Avoid sharing too much personal information. Do not take everyone, and everything they say, at face value.

Top Tips for staying safe in online communities

- Don't over share personal information on a public forum, for example your email address, telephone number, the school your child attends or specific local services you access.
- Use a pseudonym when discussing health information online and be aware of the data-sharing policies of websites where you share personal information.
- Protect yourself by customising your privacy options. You can limit who can see various aspects of your personal information online. even if you have been a user for some time, log onto your account and view and adjust the privacy settings – new settings are added over time.
- Consider the source of any information and check with your doctor before making any treatment changes, even other well-meaning parents can give out treatment information that could prove harmful.
- Be careful when sharing your child's full name online. Something they might not mind at age ten might be something they are not comfortable being available to the public at age eighteen.
- Be careful sharing photos of your child online too, for the same reason.

Resources: For practical advice and guidance to make your online experience safer look at the following:
www.getsafeonline.org Get Safe Online offers expert advice to help you protect your computer, your privacy, your family and your money from online threats www.thinkuknow.co.uk
For children to learn about internet safety – they also have a zone for parents and offer comprehensive guides which can be found here: www.thinkuknow.co.uk/parents

Moderating content

Make sure you have enough time/and volunteers to moderate an online community you set up. Nothing is more disheartening for families to finally find a community and then receive no response.

It is important to monitor closely the sites you are running (you may chose a 'closed' site for selective and invited members). It is a very good idea, within a supportive culture, to adopt some respectful and simple guidelines/ House Rules that work with your mission and empower your users.

When writing your group guidelines, things to consider include:

*Confidentiality***:** Stating what is deemed confidential and what can be shared and maybe linking to some appropriate policies, such as safeguarding.

Appropriate material: Advice your users always to use appropriate language and material that reflects well on the support group. Do share content that is publicly available but not private information.

*Venting***:** Whilst life can be stressful at times, ranting about service providers, people or issues can have harmful and even legal consequences, regardless of whether a forum is open or closed. Personal attacks, accusations, bullying, insults or posts which are hateful, threatening, contain sexual content or are offensive will not be tolerated.

Be clear upfront that any breach of the house rules will be taken seriously. There is an example of some house rules from an online support group at the end of this document.

Whilst it is best to take a 'light touch' approach, you should remove any offensive or derogatory comments. If a particular discussion is getting heated, it may be worth intervening in order to remind people to remain civil. It is also worth keeping tabs on comments or messages that may be of an overtly commercial nature

If you have clearly set out guidelines and something too controversial is 'posted' that does not fit in with your mission, it is easy to refer to these guidelines when moderating, so your decisions are as clear and consistent as possible. It may also be worth considering a complaints procedure so if someone has a grievance this can be dealt with separately to the online group via email contact. This can be included in community guidelines. For example, "If you have any complaints about our services please email help@info.com so we can deal with them most effectively. We do not deal with complaints via our Facebook page."

You can find more information on what community guidelines are here:
https://gdsengagement.blog.gov.uk/2014/06/16/5-tips-for-creating-community-guidelines/

Example of a House Rules document

This is a friendly and supportive group, and we work hard to keep it that way. Before you post, please read and follow the House Rules below.

- Please note that these rules may be updated in future. If you have any questions, please message Admin.
- Please be considerate and treat others the way you would like to be treated. This means communicating with respect and empathy, with the intent of supporting others & understanding personal boundaries.
- Please respect of all points of view and when making a comment around a sensitive subject, please take extra care to consider how the phrasing may be interpreted. Think about what you're comfortable reading – you can always remove or hide posts you don't want to see.
- This is a closed group and all care is taken to ensure members are people or parents living with xxxx condition. We do not allow members under the age of 18. We now have more than 5,000 members so please think carefully about what information and photos you post. Please consider whether your post will infringe on your child's privacy. Never post personal information (such as email addresses or telephone numbers) or information that may enable someone to locate a child or a vulnerable adult.
- Personal attacks, accusations, bullying, insults or posts which are hateful, threatening, contain sexual content or are offensive will not be tolerated.
- Comments and posts which break the House Rules may be removed at any time by the team monitoring this group; we will contact you to explain the reason, but we may ask you to leave the group if you post inappropriate messages repeatedly.
- Please keep conversations within the online community and respect each other's privacy. Don't share any information, including screenshots or advice, from this group outside of it.
- If you see anything that worries you, let us know by reporting a post or sending us a private message. We take your concerns seriously and want you to feel safe and supported.
- If you think you or someone else might need more urgent help: Samaritans (116 123 / jo@samaritans.org), call 999 or your nearest A&E department. In the event that we are concerned about your or someone else's safety, Contact may decide to contact local relevant or emergency services to inform them of our concern. This might include sharing personal details on our secure database.
- Contact cannot review all posts or comments by members and is not responsible for their contents or their use. The team at Contact will not be able to respond to your posts overnight.
- By using this group, you agree not to infringe third party intellectual property rights.
- We will not allow other organisations or individuals to repeatedly promote or advertise other groups or services. Please send a private message to Charlie (Admin) if you would like us to promote your event or service.

Thank you

Useful contacts

Advice on setting up an online community
https://www.gov.uk/government/publications/community-development-handbook/community-development-handbook

The Small Charities Coalition
Free resources on social media including *About that First Tweet: A practical guide to social media for charities and social enterprises* and *Something to Tweet About*
www.smallcharities.org.uk/resources-social-media

Know How Non-Profit
Information on social media, blogging and e-newsletters:
http://knowhownonprofit.org/campaigns/communications/effective-communications-1

Grow Your Charity Online
Free tools and resources for charity development.
www.growyourcharityonline.com/uk

TNT social media guidelines for employees
Lots of interesting information and top tips for using social media.
www.tnt.com/content/dam/corporate/pdfs/Archive/Presentations/2014/tnt_social_media_employee-guidelines_2014en.pdf

Media Trust
Lots of guidance on keeping up to date with social media.
https://mediatrust.org/communications-support/resource-hub/

CharityComms has lots of useful information about all aspects of charity communications.
https://www.charitycomms.org.uk/

Websites

A website is a good tool for informing as many people as possible of the existence of your group and what it provides. You might decide not to have a website, though, and have a blog, Facebook and/or Twitter page. Sometimes for support groups this can work well, it's easier to update and can be more interactive. Many groups now opt for this option for the fast moving content – but keep a basic web page to let families know they are there. See the earlier section, introduction to social media, for tips and free resources.

How to plan a website

- How might a website further the aims of your group?
- Who will benefit from your website: parents, young people and professionals?
- What information do you want on your website?
- How much, if anything do you have to spend?
- Who will maintain the website?

Take a look at as many parent support groups' websites as you can. This will give you ideas as to what you might like to do. If you are rare condition support group, you will find links from Contact's online Medical information to condition-specific support groups.

If you are a rare condition support group using medical information on your site

Check out the following:

Health on the Net Foundation (HON)
This organisation aims to ensure that medical information on the internet is accessible and good quality. The HON code is not an award system but a set of principles that organisations adhere to so that people accessing their information are able to judge the quality easily.
www.hon.ch/

Usability.gov
This is a US Government site managed by the US Department of Health and Human Services. You will find guidelines for making websites user friendly and accessible.
www.usability.gov

Naming your website

Having your own domain name such as www.smithsyndrome.org.uk will make your site easier to find. The problem for most people is the cost involved in having your own domain name and the technicalities of getting one.

Most groups opt for an '.org.uk' domain but some choose the more global '.org' or '.com'. Once you have registered the address it is yours for as long as you pay the annual fee. It is possible to move the site to a different ISP (internet service provider) whilst keeping the same address.

Have a look at Nominet.uk www.nominet.org.uk which gives clear information about domain names. Nominet is officially recognised as the '.uk' domain name registry by the

internet industry, users and the UK Government. Nominet ensures that each domain is only used once and all the other providers have to register through them.

There are a number of providers of domain names offering varying services. Some questions you might want to ask:

- Is there an annual fee?
- Can you move the domain name to another host?
- Do they offer online or telephone support? Some suggestions:
    www.123reg.co.uk
    www.domainnameshop.co.uk

Website design and hosting

There are many companies offering web design, hosting and support. Each one is different and you will need to shop around to find the one that suits your needs best.

> **Reading**: Article titled 'Non Profit Website Design: Examples and Best Practices' in *Smashing* Magazine available at www.smashingmagazine.com/2009/05/14/non-profit-website-design-examples-and-best-practices/ has some useful tips and information on website design.

Some groups have found that a member, or member's relation or friend, will turn out to be either a computer professional or an enthusiastic and skillful amateur. This will save you moneyand hopefully mean the site will be tailored to your needs. However, it will mean you have to work at their speed and it may take longer to get it up and running. You can go to an expert commercial provider but they can be expensive and may not necessarily produce a better result than your group can.

When designing yourwebsite think about the people who will be using it – for example, if you are supporting people with a visual impairment the site will need to be accessible to those using specialist computer equipment. Some colours are also easier to read than others. If you are using an expert to help build your site, they should be able to advise you on this.

There are a number of organisations who do web design. The Small Charities Coalition have links to useful organisations in the technology section of their website. https://www.smallcharities.org.uk/resources-technology/

Building your own website

This may sound daunting but with a little bit of will, some knowledge and a lot of enthusiasm it is possible to build your own site. There are a number of companies online offering support with this and if you search for "free web design software" a wide range of options come up.

One site you may find helpful is the BT Community Website Builder. This site allows registered UK charities, non-profit making organisations and volunteer led groups or organisations to build and maintain their own website free of charge. To qualify for use of the free service, your organisation must be from the United Kingdom, must provide a clear benefit to the local community, and be one of the following:

- a registered charity
- a non-profit making organisation
- a volunteer led group or organisation.

To start using the Community Website Builder go to: www.btck.co.uk

How do you ensure that search engines find your site?

When your site is up and running you could register it with the major internet search engines. Advice on this can be found at www.promotionworld.com

You can publicise your site on your letterhead, publications and in your email signature.

Most search engines will have a "Submit URL" or similar link where you can tell them about your website. In most cases this will be free of charge.

Search engines all work slightly differently and that is why their results vary. They will all give web pages a score based on a combination of:

- Words used in the text
- Where words appear on the page – a title or heading will score higher than text used in the body
- The number and importance of sites that link to that page.

Your score will determine the "rank" – where your page appears in the search engine results. Most search engines return a first page of ten results so your target should be to get into the top ten. If you are further down the ranking, have a look at some of the pages above yours to find ideas as to how to improve your ranking.

Expertise has a useful article on Search Engine Optimisation (SEO) which suggests ways in which you can make your website easier to find.

https://www.expertise.com/small-business/optimizing-your-website-what-every-small-business-should-know

Website Content

Information on your website should be accurate and up to date. Diarise the checking of your website at least every two or three months – or more frequently if you have date-sensitive information such as event listings. There should be an indication of when the site was last updated on the home page.

- Be clear about the purpose of your site – what do you want visitors to your site to do, for example, make a donation.
- Introduce yourself – the about us page should be short and snappy – statistics show that people spend around 30 seconds reading this page.
- Do include your contact information – e-mail and telephone details are most frequently used rather than a postal address.
- Don't use your site to dump reams of information. Aim to grab people's attention. Keep it conversational, snappy and fresh.
- Use headings and bullets to break up the text.
- Tie the content of the site to your mission statement, or your aims and objectives.
- Different audiences should be addressed on separate pages; for example, parents, professionals, young people.
- A description of the condition you support.
- Details of what your group offers to individuals and families.
- If you are in touch with the doctor who identified the condition you support, ask them to write an introduction.
- If you include information or text from another site, it is good practice to get permission first and always reference it.

Links or information you might include:

- links to websites containing relevant information such as universities, medical sites, online text books and organisations useful to your members, such as Contact, and other advice agencies. It is good practice to let them know you are linking to them and you can ask them to link to you at the same time, If you link to other websites you will need to make time to regularly check links.
- a publications list, including links to full text versions of your leaflets

- copies of your newsletters
- history of your group
- details of any patrons
- details of research into your condition
- reference material on your condition
- a news or events section. It is important to keep this up to date. Someone visiting your events section where the only event listed was in 2015 might not think you are active and may not bother to get in touch. Put your current events at the top
- stories from families or members of your group
- if you include photographs on your site make sure you have permission from the people in the photograph, especially if they show children, and the person who owns the photograph. More information on photograph permission can be found in our Holding a Family Day guide along with a sample photography permission form.

Why not get some of your parents and members involved? Ask them to look at the site and give feedback on the content and the design. Is it easy for them to find things? Is the layout clear?

Disclaimers, terms and conditions and privacy

A disclaimer advises readers of what the organisation's responsibilities are. This sounds scary but you should be clear with your audience that you are not medical professionals and that your site is to provide emotional support and share experiences.
'Although great care has been taken in the compilation and preparation of all information to ensure accuracy, [organisation name] cannot accept responsibility for any errors or omissions. All medical information written by [organisation name] is reviewed and approved by a medical expert.'

'Any medical information is provided for education/information purposes and is not designed to replace medical advice. You should obtain further information from your medical practitioner.'

If you have links to other websites, you should also have a further disclaimer:

'Any links to external websites have been carefully selected but are provided without any endorsement of the content of those sites.'

Similarly, the terms and conditions set out what you are offering and what you expect from people using your site, for example, can they copy information from your site? If you offer forums or chat rooms on your website you should also give guidelines on how people should behave, details of the moderation process and how people can raise concerns.

If you collect any data on your visitors, a privacy statement will outline what you do with this information. If you keep information, what will you use it for?

Many examples are available on the internet and you can use these to create guidelines that are most relevant for your group.

Tracking visitors

Some groups find it useful to track who comes to their site, where they come from (whether from a web browser or another website) and which pages are more popular. A number of site hosts have this facility and provide the service free. Statistics from your website can be used to help you apply for funding and help develop your website in the future. The most widely recognised provider is Google Analytics and this may carry more weight with funders.

Useful Resources

BT Community Web Kit
As part of BT Community Web Kit you'll receive lots of free resources to build a website with unlimited pages and up to 500 pictures. You'll also find Welsh language options.
www.btck.co.uk/

Charity and biscuits
Charity and biscuits is a collective of designers, coders and writers who specialize in helping charities create wonderful websites and compelling digital content.
www.charityandbiscuits.com/charity-website-toolkit/

NCVO Knowhow
Advice from NCVO about creating an online presence.
https://knowhow.ncvo.org.uk/how-to/how-to-quickly-and-cheaply-create-a-web-presence-for-your-charity

Small Charities Coalition
Small Charities Coalition have links to several useful resources in their technology section.
https://www.smallcharities.org.uk