

Working together for siblings



Foto: Fotolia/Sonyja Frutson

Practice manual

„Focus on children with chronically ill siblings or siblings with special needs“

This new manual helps experts set up offers for supporting affected siblings. It can be used in various medical contexts.



Tom is 18 and delighted that he is now allowed to drive a car. When asked where he's driving to and with whom, he replies: „with my brother“. Tom's brother has Down syndrome.

The manual „Focus on children with chronically ill siblings – a family-oriented advisory concept“ offers this and many other such case studies. The authors, Birgit Möller, Marlies Gude, Jessy Herrmann and Florian Schepper, present a comprehensive introduction to the subject. They also describe the advisory process, including diagnostic investigations and therapy, on the basis of examples from their own practices. The manual offers a child-centred and family-oriented advisory approach, and shows how siblings and their families can be given

targeted help. The important diagnostic steps and work material in the appendix (also available as a free download) round off the high practical value of this book.

The advisory concept is aimed at psychologists, social education and welfare workers, doctors, and those employed in the psychosocial sector as well as associations, charitable organisations and self-help groups in this field. With its family-centred individual approach, this book is a valuable addition to existing standardised group offers.

Information about the manual:

2016. 202 pages with 7 figures and 5 tables, incl. download material, paperback; €25.00
ISBN 978-3-525-40199-6
www.v-r.de/de/geschwister_chronisch_kranker_und_behinderter_kinder_im_fokus/t-0/1038082/

New publication: Practical manual SiblingsDAY

The offer for newcomers to accompanying siblings of chronically ill, severely ill children and/or children with special needs is based on the SiblingsCLUB model. The focus is on exchanges between the children themselves and boosting their personal resources using playful and creative methods. The next newsletter will include comprehensive information on the book.



Book reviews

Der GeschwisterTAG [SiblingsDAY]
Selbstverlag Bundesverband
Bunter Kreis e.V.
Format: hardcover,
144 pages + CD with templates
ISBN 978-3-9816958-3-0

Editorial

Dear friends of FamilyTies,

The subject of „prevention“ is playing an increasingly important role in 2016. The German Prevention Act has now made it possible for statutory health insurers to reimburse courses that are certified as preventive offers and conducted by qualified experts. Both of these apply to „GeschwisterTREFF“ [SiblingsFORUM] and the „SuSi“ training programme to help cope with stress if an expert runs the programmes for siblings. The reimbursement of these services for siblings are currently on the agenda of most health insurances. The alliance for siblings (ISPA, Siblings Association and Novartis' FamilyTies foundation) is working actively to ensure that as many statutory health insurers as possible do this. This will give the organisations a plannable basis and relieve pressure on the household budgets of the affected families.

2016 has also seen the publication of new important books that are very valuable additions to the group offers mentioned above: the basic manual „Focus on children with chronically ill siblings and siblings with special needs– a family-oriented advisory concept“ is aimed at the healthcare sector: the FamilyTies' parents' guide is available for parents and relatives of siblings. And fresh from the press: the practical manual „GeschwisterTAG“ [SiblingsDAY].

We will continue to work together with our network partners to make all the existing reviewed material widely available.

Together for siblings!



Adib Jacob
Chairman of the
Novartis Foundation
FamilyTies



Irene von Drigalski
Managing Director
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Practice report

Guide for parents of siblings of chronically ill children or children with special needs

The Novartis FamilyTies foundation joined up with the Institute for Social Medicine in Paediatrics Augsburg (ISPA) to publish a parents' guide. The guide has been developed for mothers and fathers who are looking for ideas and inspiration on how best to overcome the special challenges that their families are faced with.

It combines expert knowledge with the experiences of affected parents. The parents' guide has deliberately not been written as an adjunct to treatment. On the contrary, it is a compilation of information, suggestions and recommendations on the subject of siblings that is intended to help parents better understand and cope with their individual situations. The know-

how presented here stems from the practical experiences of seasoned parents and the knowledge of experts who accompany siblings.

The guide is available as a free download at www.stiftung-familienbande.de. We also look forward to responses to the corresponding questionnaire to help us continually improve the parents' guide.



The author of the guide is Isolde Stanczak. She has many years of professional experience in developing and conducting training

and further education programmes for expert staff in the public health sector, patient education courses, and as a case manager and coach. She is a member of the team headed by Andreas Podeswik at the ISPA, the FamilyTies foundation's most important partner from the very outset. It is her responsibility to organise the content of the information service on the subject of siblings for affected families and specialist circles.

LICHTBLICK-Freizeit [RAY OF HOPE-leisure time] by the AOK

Emerging stronger from adventures

Siblings of chronically ill children on educational nature tours in the Eifel region.

We all know the feeling, the joy we feel after having come through an adventure together and overcoming challenges on expeditions. 23 siblings revelled in this feeling at LICHTBLICK's Easter spree in the Eifel region. They rambled every which way through the woods, followed a bubbling stream, and worked together to build a dam. They prepared firewood from felled trees for a camp fire, and they worked away fearlessly with the saw. They were accompanied by Burgey, the forester from the Raffelsbrand Youth Forest Home, who taught them all about nature as a habitat and a provider.

This special leisure time offer is centred on the siblings. LICHTBLICK has been supporting member families of AOK Rheinland/Hamburg with chronically ill children since 1996. The siblings have always been at the focus of

their work. LICHTBLICK's leisure time offers are held in co-operation with the Deutsche Leukämie-Forschungshilfe [German Leukaemia Research Aid] and the Aktion für krebserkrankte Kinder e. V., [Campaign for Children with Cancer].

One of the important facets of the Easter spree is building up their self-esteem to give them confidence in their own abilities and help them tap their own personal resources. The siblings gain new strength from being outdoors and profit from the company of the other children who feel similarly and are also in a special situation due to the illness of a brother or sister. This makes it easier for them to talk about their own circumstances. Jonas, one of the participating children, made it perfectly clear „I don't feel so alone here. I've never talked about my brother's illness to anybody before“.



LICHTBLICK by the AOK Rheinland/Hamburg

Accompanies families with seriously and chronically ill children and also answers questions about services and contractual issues in the fields of social work and social insurance.

Telephone: 0800 3737374

(free of charge)

Email: lichtblick@rh.aok.de

www.vigolichtblick.de

FORUM



Winners of the 2015 Promotional Award

Support for the whole family system



The families of children with cancer often also have to face a long life of suffering. The phönikks foundation offers psychological support in the form of family therapy.



Nobody is prepared for the diagnosis of cancer. The uncertainty and the intensive medical treatment are a burden on the entire family. Even after the acute illness has been conquered, the emotional stress can persist for a long time, and alters the lives of parents, children, partners and siblings. The continuing risk of relapse can leave a deep sense of uncertainty in all aspects of life for the affected.

However, they can no longer be given any psychological care at the hospital because the hospital is no longer responsible during the phase following acute treatment. Siblings usually fall out of the system completely, or only individual offers are available. This is where the offer of help from phönikks kicks in. phönikks offers psychotherapeutic counselling or group offers. Because: „Talking with others about the illness and its consequences helps the affected families“, said Rainer Simeit from the phönikks foundation.

By opening up to others you can also accept help yourself. This enables

children and their parents to come to terms with their fears and all they have experienced. The foundation also offers additional therapeutic activities like music therapy, soul writing and art projects to build a bridge for the soul. The aim is to „draw the family closer together and say yes to life“ and „to come to terms with what has happened so that the family can come closer together to become healthy“.

The phönikks foundation was awarded the 2015 FamilyTies Promotional Award for this offer.

- Around 200,000 children in Germany find out every year that a parent has cancer.
- 20 – 30% of children with a parent who has cancer develop marked stress disorders and conspicuous behavioural changes.

Key data

Established: 1986
Target group: the entire family
Address: phönikks, Stiftung und Beratungsstelle, Kleine Reichenstr. 20, 20457 Hamburg
Telephone: 040 44 58 56
Email: bs@phoenikks.de
www.phoenikks.de

Siblings Olympics 2016

„Alex keeps up very well in basketball [...]. But I do give him some help with the agility exercises, for example the egg and spoon race, when I help him over the obstacles. But Alex is better in the goal wall shooting game“.

Katharina (13) talking about her brother Alexander (16) who has Down syndrome

Together with over 300 other participants, Katharina and Alexander once again attended the Siblings Olympics this year that is sponsored by the FamilyTies foundation. The Siblings Olympics is held as part of the Down's Athletes Festival, a HEXAL initiative.

This is where pairs of siblings compete against each other in various disciplines such as knocking tin cans down, goal wall shooting, the agility parkour, or basketball. For more information visit:

www.down-sportlerfestival.de



Over 100 specially trained staff for siblings!

102 people have successfully completed the further training course „Specialist for siblings of ill people and/or people with special needs“ over the last 4 years. This is a further training concept for specialists in the welfare and public health sectors. Over 120 specialists all over Germany are expected to have been trained in the subject of siblings by autumn 2016 – another important milestone on the way to nationwide coverage with high quality care for siblings.

The course „Specialist for siblings“ was supported by the FamilyTies foundation and developed by the Institute for Social Medicine in Paediatrics Augsburg (ISPA) together with practitioners from the Sozialverband VdK Bayern e.V. [Bavarian Social Association VdK] and the Bildungs- und Erholungsstätte Langau e.V. [Educational and recreational centre in Langau].

Recommended reading

Book tip from Marlies Winkelheide:

It's almost exactly the same in heaven

by Ulf Stark



Ulf never met his sister. She died before he was born. He'd like to imagine what his sister was like, he longs for his sister.

He sends a message into space and meets a girl who is exactly as he had always imagined his sister to be. A moving story about death and missing people, about the joy of meeting somebody, and about a question that many siblings ask themselves.

Text by Ulf Stark

Bound with colour illustrations.
by Leonard Erlbruch



Stiftung
FamilienBande
Gemeinsam für Geschwister

Publishing details

Content: FamilyTies network

Editing and realisation: COMMPartners, info@commpartners.de, Holzkirchen

Publisher: Novartis FamilyTies Foundation
Öflinger Straße 44, 79664 Wehr/Baden, Germany

We value your opinion!

Please let us know what aspects of FamilyTies NEWSLETTER you have enjoyed or what could have been done better. If you would prefer not to receive the newsletter, please send a brief e-mail to:
info@stiftung-familienbande.de

Help for siblings

Search for FamilyTies offers

The „Colourful Map of Germany“ with offers must become denser in the new federal states.

When affected families of siblings start looking for support near them, if a paediatrician or GP would like to arrange an offer for a sibling, or if firms in a certain region are looking for a project to support – they will all find something in the search for FamilyTies offers. This is where organisations can register their offer for siblings – be it a carefree afternoon of horse riding for siblings, regular siblings' days, or group offers where people can work on the content.

There are now 290 offers (at the end of June 2016) registered in the FamilyTies' search for offers. We started off with 34 offers in 2011. The number of offers has increased by 40% in the last two years alone. One new aspect is that organisations in other countries like Switzerland and Austria have become aware of us, and have listed offers with us. The number of organisations involved has also grown – by 60% to 171. This means: more variety and thus another step on our way to a colourful map of Germany full of offers with widely differing approaches.



But despite this heartening increase, there is an imbalance between the various federal states. The majority of offers (60%) are shared among North Rhine-Westphalia, Bavaria and Baden-Württemberg. In contrast, not one single offer has been registered in Mecklenburg-Western Pomerania, and just one in Saarland. Conurbations have a clear advantage. But in rural districts it is more difficult to set up and maintain offers covering larger areas. This is why the FamilyTies foundation is now trying to shift the future focus to regions with few offers.

NEU in Datteln

Alle 290 Angebote für Geschwister finden Sie hier.

Für Einrichtungen:
Angebote registrieren

Für Geschwister und ihre Familien:
PLZ Angebote in Ihrer Nähe finden

It is so simple to register: anybody who wants to register a new offer, or even one that has been on the books for some time, can do this with just a few clicks on the FamilyTies homepage. The details are then checked and activated as soon as everything is complete and any questions have been answered.

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