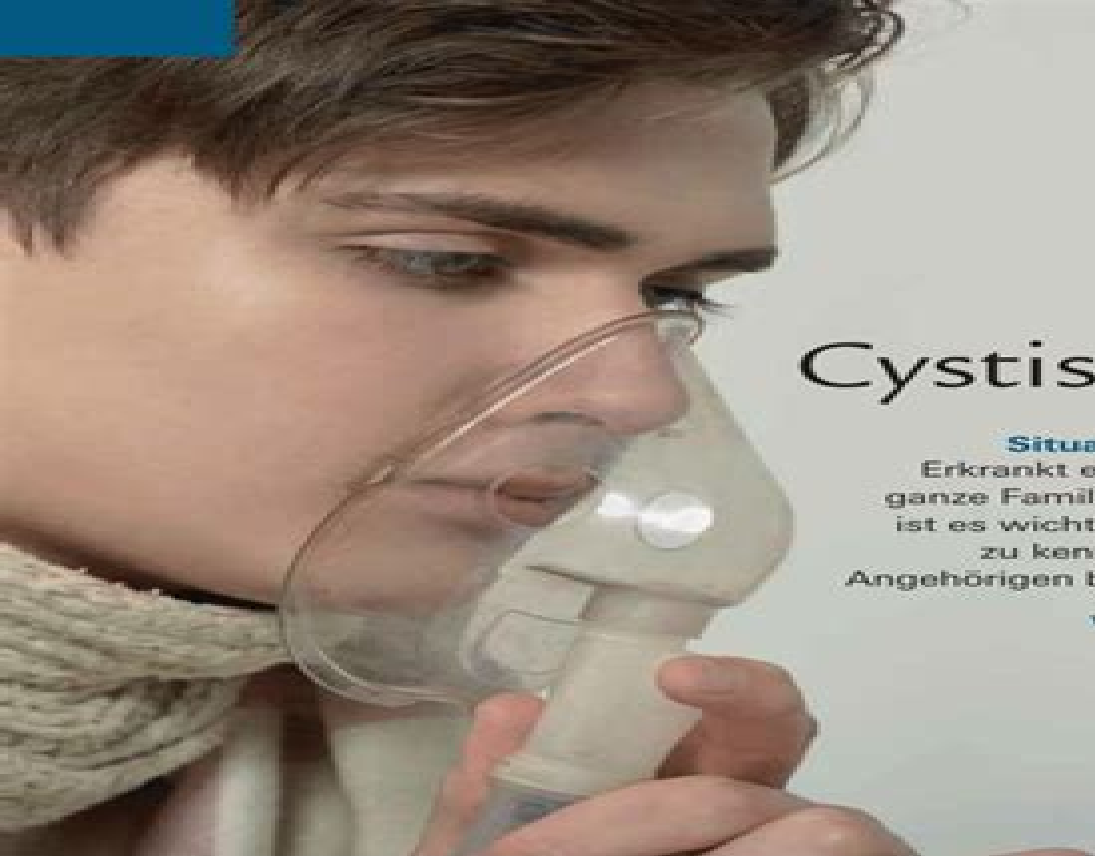




Leben mit Cystischer Fibrose

Situation der Kinder und ihrer Familien

Erkrankt ein Kind an Cystischer Fibrose, ist die ganze Familie betroffen. Für Pflegefachpersonen ist es wichtig, die typischen Herausforderungen zu kennen, um das betroffene Kind und die Angehörigen bestmöglich unterstützen zu können.

Von Laura-Sabrina Weiß und Nicole Ortner

Die Krankheit Cystische Fibrose, auch unter dem Namen Mukoviszidose bekannt, ist in den westlichen Ländern die häufigste autosomal rezessive Erkrankung. Sie betrifft einen von 2 500 Neugeborenen (Härche et al. 2005). Zurzeit leben in Österreich zirka 800 Betroffene (Renner 2014), in Deutschland etwa 8 000 (Merk & Schubert-Zsilavecz 2011).

Die Lebenserwartung konnte aufgrund von Fortschritten in Therapie und Prävention von zehn Jahren auf durchschnittlich 38 Jahre gesteigert werden (Bourke & Burns 2011) – auch wenn die Cystische Fibrose nur symptomatisch behandelt werden kann. Um das Fortschreiten der Krankheit so lange wie möglich hinauszuzögern, bedarf es regelmäßiger Antibiotikaeinnahmen, Vitamin- und Enzymsubstitutionen, einer hochkalorischen Ernährung, verschiedener Inhalationen und regelmäßiger Physiotherapie, speziell Brustraumphysiotherapie.

Die Perspektive erkrankter Kinder und Jugendlicher

Die Cystische Fibrose zeigt sich durch Hustenanfälle, häufige Medikamenteneinnahme und körperliche Schwäche. Diese Symptome ziehen viel Aufmerksamkeit auf sich, sodass die Betroffenen oft mit Fragen konfrontiert werden. Vor allem im Kindesalter ist es schwierig, die Fragen von Gleichaltrigen zu beantworten, weil die Erkrankung selbst noch nicht richtig verstanden wird. Oftmals resultiert daraus eine Hürde, Freundschaften in der Peergroup zu finden und nicht ausgeschlossen zu werden (D'Auria et al. 1997). Viele Menschen glauben auch fälschlicherweise, sich mit der Erkrankung anstecken zu können, und meiden daher den Kontakt mit den Erkrankten (Pizzignacco & Lima, 2006).

Aufgrund schlechter Erfahrungen entwickeln betroffene Kinder und Jugendliche oftmals Ängste vor möglichen Reaktionen und ihre eigenen Strategien, um die

Cystische Fibrose Leben Mit Einer Chronischen Krankheit

**Cornelia von Hagen, Hans Peter
Schwarz**



Cystische Fibrose Leben Mit Einer Chronischen Krankheit:

Psychische Entwicklung bei chronischer Krankheit im Kindes- und Jugendalter Cornelia von Hagen, Hans Peter Schwarz, 2009 In den westlichen Industrienationen leiden etwa 20 Prozent aller Kinder und Jugendlichen unter mindestens einer chronischen somatischen Erkrankung Aufgrund der vielfältigen Belastungen besteht bei den betroffenen Kindern und Jugendlichen ein erhöhtes Risiko zusätzlich eine psychische Störung zu entwickeln Die adäquate Betreuung stellt somit eine besondere Herausforderung für das Gesundheitswesen dar Von zentraler Bedeutung ist dabei das Bemühen ein hohes Mass an Lebensqualität zu gewährleisten Im Mittelpunkt des Buches steht zum einen die Darstellung der psychischen Entwicklung bei ausgewählten Krankheitsbildern zum anderen wird ein Überblick über relevante psychologische Präventionen und Interventionsmethoden gegeben Cystische Fibrose D. Reinhardt, M. Götz, R. Kraemer, M. Schöni, 2013-03-12 Mit diesem

Werk ist es den Herausgebern gelungen das erste umfassende Handbuch zur cystischen Fibrose auf dem deutschsprachigen Markt zu veröffentlichen Für diese Experten aus Deutschland Österreich und der Schweiz bringen sie die beste inhaltliche und didaktische Qualität Neben den molekularen Grundlagen und der Pathophysiologie der cystischen Fibrose gibt dieses Buch einen detaillierten Einblick in Diagnostik Verlauf Therapie und die psychosozialen Aspekte dieser Krankheit Das Handbuch basiert auf den Standards der großen Therapiezentren und ist für den in Klinik und Praxis tätigen Arzt ein unverzichtbares Nachschlagewerk **Cystische Fibrose** Gustel Matthias Schmitt, 1991 Schluss mit Lust und Liebe? Birgit

Delisle, Gerhard Haselbacher, Nikolaus Weissenrieder, 2003-01-01 Wenn ich gewusst hätte dass Sex nach meiner Herzoperation nicht schädlich ist hätten wir uns eine Menge Frust erspart klagt ein Mann Die Ärzte haben den Patienten mit guten Wünschen entlassen ohne ihn darüber aufzuklären was er sich sexuell zutrauen kann Sexualität haben unsere Bewohner nicht die sind ja schwer behindert sagt eine Mitarbeiterin einer Behinderteneinrichtung und spricht ihnen sexuelle Bedürfnisse damit ab Gesellschaftlich gewachsene Vorstellungen sind für solche verfehlten Einschätzungen mit verantwortlich Oft fehlt das Wissen über die Auswirkungen von Operationen oder chronischen Krankheiten auf das sexuelle Empfinden oder über Sexualität bei Körperbehinderungen Ärzte Betreuer und Sozialpädagogen sind gefragt die eigenen Informationsdefizite auszugleichen und Patienten oder Menschen mit einer Behinderung aufzuklären und zu beraten In diesem Band kommen unterschiedliche Autoren zu Wort Da geben Betroffene Einblick in ihr Empfinden sprechen von den Verletzungen die ihnen zugefügt wurden und von ihren Bedürfnissen die sie sich erfüllen Fachärzte klären über die Folgen auf die bestimmte Erkrankungen wie Diabetes Rheuma oder Krebs auf das sexuelle Erleben haben können Pädagogen zeigen wie unverkrampft der Umgang mit Sexualität in einem Wohnheim gelingen kann Damit noch lange nicht Schluss ist mit Lust und Liebe

Therapie psychischer Störungen bei Kindern und Jugendlichen Helmut Remschmidt, 2010

Körperbehindertenpädagogik Harry Bergeest, Jens Boenisch, Volker Daut, 2011-06-16 Der etablierte Terminus Körperbehindertenpädagogik bezeichnet die Pädagogik für Menschen mit Beeinträchtigungen der körperlichen und motorischen

Entwicklung Damit ist sie Teil der umfassenden Rehabilitation von Menschen mit von Geburt an vorhandener oder später eingetretener körperlicher Schädigung oder chronischer Erkrankung Die Schädigung kann zu Erschwernissen der kognitiven emotionalen und sozialen Lebensvollzüge führen und so die Selbstständigkeitsentwicklung nachhaltig beeinflussen Die Körperbehindertenpädagogik bietet spezifische Unterstützung beim Erwerb von Kulturtechniken der Entwicklung eigenständiger Kreativität und sozialer Orientierung Im Sinne der Inklusionsbestrebungen soll sie betroffene Menschen befähigen ihren eigenen sinnvollen Weg innerhalb der Gesellschaft zu finden Die Leser erhalten einen Überblick über den Gesamtkomplex Personengruppe Entwicklungsbedingungen pädagogische Intervention Inklusion Elternkontakt Professionalisierung der Pädagogen sowie theoretische Grundpositionen auf der Basis eines konstruktivistisch fundierten Erziehungsbegriffs Das Standardkompendium erscheint in erweiterter Form nunmehr in Zusammenarbeit dreier Autoren die seit Jahren dieses Arbeitsfeld mit prägen *Current Catalog National Library of Medicine (U.S.)*, 1993 First multi year cumulation covers six years 1965-70 Vergessene Pubertät Ruth Draths, 2012-01-01 Ein frauenärztlicher Blick auf Pubertät Sexualentwicklung und Verhütung Acht Jugendliche acht unterschiedliche Lebensgeschichten acht unterschiedliche Erkrankungen Bei Jugendlichen mit einer Behinderung oder chronischen Krankheit wie Spina bifida Zystischer Fibrose oder Krebserkrankungen wird die Pubertät durch die medizinischen Probleme oft in den Hintergrund gedrängt Aber Aischa Selin und Max sind in der Pubertät und sie haben dieselben Wünsche und Bedürfnisse wie alle anderen Jugendlichen auch Sie benötigen eine speziell fundierte Beratung Die erfahrene Frauenärztin öffnet den Blick in diese besonderen Entwicklungsprobleme Vom ersten Gespräch über die körperliche Untersuchung bis zur persönlichen Beratung über intime Fragen von Sexualität Fruchtbarkeit und Verhütung wird der Leser in die jugendgynäkologische Sprechstunde mitgenommen Anliegen des Buches ist es Jugendliche und auch ihre Eltern und Betreuungspersonen früh und ausführlich zu informieren Alles wird für Jugendliche gut verständlich erklärt medizinische Hintergrundinformationen sind besonders hervorgehoben so dass auch Fachleute in der Beratung von Jugendlichen mit speziellen Bedürfnissen profitieren können Mit dem Kauf dieses Buches unterstützen Sie firstlove ein Präventionsprojekt für Jugendliche **Psychische Störungsbilder bei Kindern und Jugendlichen** Volker Tschuschke, 2019-07-31 This volume documents the knowledge currently available on the differential effectiveness of various psychotherapeutic procedures for 22 clinical pictures in psychology At the same time it attempts to build a bridge between clinical practice and research The pathogenesis of all the disorders is dealt with in a way that takes all the different schools into account thus providing a broad based framework of knowledge and explanation for psychological disturbances in adults The author provides a detailed overview of the current state of knowledge on the development and treatment of psychological disorders in children and young adults Symptomatology frequency of occurrence different explanatory approaches comorbidities diagnostic procedures interviewing and test procedures treatment options and prospects for success are presented through a critical examination of evidence based research The author aims to provide all practising

paediatric psychotherapists with a critical work in scientific methodology that allows them to evaluate the state of research on the various disorders in a nuanced but nevertheless comprehensible way *Journal of Behavioral Medicine* ,2003

Unveiling the Energy of Verbal Artistry: An Psychological Sojourn through **Cystische Fibrose Leben Mit Einer Chronischen Krankheit**

In a world inundated with monitors and the cacophony of instantaneous interaction, the profound power and emotional resonance of verbal beauty often fade in to obscurity, eclipsed by the continuous assault of sound and distractions. However, situated within the lyrical pages of **Cystische Fibrose Leben Mit Einer Chronischen Krankheit**, a interesting work of literary beauty that pulses with natural feelings, lies an wonderful journey waiting to be embarked upon. Penned by a virtuoso wordsmith, this enchanting opus courses readers on an emotional odyssey, softly exposing the latent potential and profound impact embedded within the intricate internet of language. Within the heart-wrenching expanse of the evocative evaluation, we can embark upon an introspective exploration of the book is main themes, dissect their captivating publishing design, and immerse ourselves in the indelible impression it leaves upon the depths of readers souls.

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Table of Contents Cystische Fibrose Leben Mit Einer Chronischen Krankheit

1. Understanding the eBook Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - The Rise of Digital Reading Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Advantages of eBooks Over Traditional Books
2. Identifying Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Exploring Different Genres
 - Considering Fiction vs. Non-Fiction
 - Determining Your Reading Goals
3. Choosing the Right eBook Platform
 - Popular eBook Platforms
 - Features to Look for in an Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - User-Friendly Interface
4. Exploring eBook Recommendations from Cystische Fibrose Leben Mit Einer Chronischen Krankheit

- Personalized Recommendations
- Cystische Fibrose Leben Mit Einer Chronischen Krankheit User Reviews and Ratings
- Cystische Fibrose Leben Mit Einer Chronischen Krankheit and Bestseller Lists
- 5. Accessing Cystische Fibrose Leben Mit Einer Chronischen Krankheit Free and Paid eBooks
 - Cystische Fibrose Leben Mit Einer Chronischen Krankheit Public Domain eBooks
 - Cystische Fibrose Leben Mit Einer Chronischen Krankheit eBook Subscription Services
 - Cystische Fibrose Leben Mit Einer Chronischen Krankheit Budget-Friendly Options
- 6. Navigating Cystische Fibrose Leben Mit Einer Chronischen Krankheit eBook Formats
 - ePub, PDF, MOBI, and More
 - Cystische Fibrose Leben Mit Einer Chronischen Krankheit Compatibility with Devices
 - Cystische Fibrose Leben Mit Einer Chronischen Krankheit Enhanced eBook Features
- 7. Enhancing Your Reading Experience
 - Adjustable Fonts and Text Sizes of Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Highlighting and Note-Taking Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Interactive Elements Cystische Fibrose Leben Mit Einer Chronischen Krankheit
- 8. Staying Engaged with Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Joining Online Reading Communities
 - Participating in Virtual Book Clubs
 - Following Authors and Publishers Cystische Fibrose Leben Mit Einer Chronischen Krankheit
- 9. Balancing eBooks and Physical Books Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Benefits of a Digital Library
 - Creating a Diverse Reading Collection Cystische Fibrose Leben Mit Einer Chronischen Krankheit
- 10. Overcoming Reading Challenges
 - Dealing with Digital Eye Strain
 - Minimizing Distractions
 - Managing Screen Time
- 11. Cultivating a Reading Routine Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Setting Reading Goals Cystische Fibrose Leben Mit Einer Chronischen Krankheit
 - Carving Out Dedicated Reading Time
- 12. Sourcing Reliable Information of Cystische Fibrose Leben Mit Einer Chronischen Krankheit

- Fact-Checking eBook Content of Cystische Fibrose Leben Mit Einer Chronischen Krankheit
- Distinguishing Credible Sources

13. Promoting Lifelong Learning

- Utilizing eBooks for Skill Development
- Exploring Educational eBooks

14. Embracing eBook Trends

- Integration of Multimedia Elements
- Interactive and Gamified eBooks

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