

Task Force for adults with congenital heart defect

Experts develop guidelines for adequate medical care / adults with congenital heart defects still do not receive adequate medical care

The group of adults with congenital heart defects grows - yet still can not be provided with adequate medical care. An interdisciplinary Task Force has been established to develop guidelines for adequate medical care structures and to establish a new additional notation for cardiologists.

In earlier years only 10 % of the children with serious congenital heart defects achieved adulthood, nowadays 85 – 90 %.

Now, out of approximately 230.000 affected patients in Germany already 140.000 achieved adulthood. These patients are not healed at all said Professor Günter Breithardt from the University-Hospital Münster at a cardioly congress. They still have a high risk of heart-insufficiency. 26 % die after required follow-on operations. 22 % die due to sudden cardiac death.

Many patients barely attend medical appointments or decide to see the doctor too late after the medical care by children-cardiologists is no longer possible. According to cardiologists, adult-cardiologists are not familiar adequately with the difficulties of the disease:

The patients fall into a medical-care-gap.

Furthermore scientifically evident studies about how to treat adults with congenital heart defects barely exist. In addition patients are faced with difficulties in choice of career, questions of roadworthiness or pregnancy. Many insurances don't accept contracts with patients and there is also a lack of psycho-social care.

A Task force under adopted these questions. It consists of cardiologists, children-cardiologists, heart surgeons, clinicians and practicing specialists, parent-/patient representatives. It developed guidelines for medical care structures. It also analyses what family doctors and internal specialists should cover and additionally where specialists are needed. Together with Austrian and Swiss colleagues a combined guideline was established. In future cardiologists can obtain the additional notation "adults with congenital heart defects". Scientific studies will be initialized at the competence network congenital heart defects (Kompetenznetz angeborene Herzfehler).

Obtain more information: http://www.bvhk.de/dokument_8.38.662.html or www.kompetenznetz-ahf.de