Stichting Epilepsie Instellingen Nederland

Epilepsie Dachverband Österreich

Caritas Malta Epilepsy Association

Interessenvereinigung fur Ansfallskranke in Koln e.V.

epilepsy connections
Supporting people with epilepsy

EPI-PICTO
Pictorial Guide To Epilepsy

Funded by the Erasmus+ Programme of the European Union

EPIPICTO: a pictorial guide for adults with epilepsy

Curriculum and Learning Guide

Erasmus + Project 2017-1-MT01-KA204-026946

INTRODUCTION

What is EPIPICTO?

Epilepsy is one of the most common chronic neurological disorders affecting around 1% of the population worldwide. This project aims to address adults with epilepsy who are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe and persons with low literacy levels and low health literacy.

These persons are marginalised because of their health conditions, stigma and discrimination. The project will contribute to the social inclusion of these persons by using a pictorial guide to overcome language barriers and literacy issues. This will improve their access to social, health, education and employment services and help them to better manage their epilepsy. It will result in a better quality of life for these persons.

The project brings together five European epilepsy organisations from Austria, Germany, Malta, the Netherlands and Scotland.

This guide complements the aims of the Education Taskforce of the International Bureau for Epilepsy (IBE) made up of laypersons and professionals and has over 140 Chapters worldwide, all working towards creating a better life for the person with epilepsy (PWE). Moreover, the International League Against Epilepsy (ILAE), founded in 1909, recognizes education as one of its missions "to ensure that health professionals, governments, and the public world-wide have the essential educational and research resources to understand, diagnose and treat persons with epilepsy".

In both organizations, education has been identified as a key tool for achieving their goals, at both professional and community levels.

The IBE Education Commission Task Force (IBE-ECTF) was set up to improve the situation of people with epilepsy and their families through their own education, training of professionals dealing with epilepsy, education of officials (e.g. employment officials), and lay persons with the concomitant effect of improving awareness and fighting stigma.

It is to be noted that this Pictorial Guide, fits in well with ILAE competency-based curriculum for epileptology just published by the ILAE Task Force for Epilepsy Education (EpiEd). Most especially, it tackles competency 2.0 which addresses counselling (Blumke et al, 2019). This curriculum was developed following a survey of the currently existing ILAE-endorsed teaching activities which identified a significant gap in education of basic knowledge of epileptology. It is being envisaged that virtual campus will be constructed around the curriculum, integrating the various educational activities of the ILAE in order to achieve the educational goal of the ILAE. EPIPICTO can be used as a paedalogical tool in this regard.

Table 1: Competency 2.0: ILAE competency-based curriculum for epileptology. ILAE Task Force for Epilepsy Education (EpiEd) (Blumke et al, 2019).

2.0 Counselling	
2.1	**Understand and address the culturally-appropriate aspects and consequences of the diagnosis of epilepsy, including stigma**
2.2	**Provide guidance on specific issues related to epilepsy** 2.2.1 Provide guidance on social issues including school integration, work, legal, and related aspects 2.2.2 Provide guidance regarding lifestyle matters, such as driving, sports, alcohol, stress, sleep, drug use, and non-adherence 2.2.3 Provide guidance regarding safety issues related to seizures
2.3	**Communicate information about the causes and consequences of the specific type of epilepsy and its treatments** 2.3.1 Communicate to patients and families, as appropriate, about the epidemiology of epilepsy 2.3.2 Educate patients and family about the disease specifics (*e.g.* prognosis, self-limiting, risk factors, *etc*.) 2.3.3 Educate caregivers about the clinical condition and its management 2.3.4 Educate workplace or school stakeholders concerning the patient's needs 2.3.5 Provide information to patients regarding potential adverse effects of antiepileptic drugs 2.3.6 Counsel patients and family regarding the risks and benefits of epilepsy surgery
2.4	**Counsel patients about medication taper and discontinuation** 2.4.1 Advise patients in remission 2.4.2 Advise patients with uncontrolled seizures
2.5	**Recognize when to refer patients for higher level of care (*e.g.* prolonged video-EEG recording, pre-surgical evaluation, uncontrolled epilepsy, lesional epilepsy, epileptic encephalopathy, psychiatric comorbidity, genetic counseling, *etc*.)**
2.6	**Counsel women of childbearing age about the implications and management of epilepsy** 2.6.1 Provide guidance regarding contraception 2.6.2 Provide guidance regarding pregnancy, including teratogenicity of the various antiepileptic drugs 2.6.3 Provide guidance regarding post-partum and child care 2.6.4 Provide guidance regarding antiepileptic drugs and hormonal interactions
2.7	**Provide information and explain to a patient the concept of sudden unexpected death in epilepsy patients (SUDEP) and advise on the associated risks**
2.8	**Provide counseling on issues specific to the elderly with epilepsy** 2.8.1 Identify and provide counseling on issues related to comorbidities 2.8.2 Identify and provide counseling on issues related to drug interactions
2.9	**Provide counseling specific to children with epilepsy and their parents, according to the epilepsy types (*e.g.* lifestyle, cognitive function and prognosis)**
2.10	**Provide counseling and information in relation to PNES to patients and families** 2.10.1 Understand and address the culturally appropriate aspects and consequences of the diagnosis of PNES 2.10.2 Communicate information about the causes and consequences of PNES and the potential of psychological treatment 2.10.3 Counsel patients about tapering inappropriate antiepileptic drugs and the role of other medications (anxiolytics, antidepressants) in PNES

WHY THE NEED FOR THIS CURRICULUM GUIDE?

The aim of this curriculum and learning guide is to facilitate the use of the EPIPICTO pictorial guide among trainers. EPIPICTO, is a pictorial guide to epilepsy for people who have limited literacy skills or who are new arrivals in Europe with limited understanding of the local language. The guide can be used in conjunction with various pedagogical tools such as role playing, audiovisual aids, small group exercises, and moderation sessions to facilitate the process and make it more interactive. There should be regular feedback and evaluation following such training activities since this will important and key feedback on the pictorial guide from partners and IBE and grass roots contacts. This guide can be used by various trainers such as psychologists, social workers, nurses, pharmacists, teachers and persons with epilepsy and their families.

HOW TO USE THE GUIDE?

Before using EPIPICTO, it is important that all trainers:

- Should familiarise themselves with the content of this curriculum and learning guide
- Should make sure their understanding of epilepsy is up to date by undertaking a short training course or researching a reliable website such as Epilepsy Action UK.
- Be aware of the limits of their knowledge and be ready to signpost the person to local sources of help. Check for a list of support groups in your area by going through the IBE website www.ibe-epilepsy.org.
- Make sure they understand and are able to address the culturally-appropriate aspects and consequences of a diagnosis of epilepsy, including stigma
- Consider who will be at the end user during the training session e.g. a partner/carer/friend who could support the person to manage epilepsy, seizures and medication
- Think about how you are going to use EPIPICTO and how much time you will need to work through it

It is to be kept in mind that EPIPICTO is not a substitute for medical advice from a healthcare professional but it provides basic information that will help staff working with target audiences to start a conversation about epilepsy. All this will be undertaken by common and mutual learning in intercultural contexts, which will aid to promote transfer of knowledge and experience and strengthen the educational dimension that will then ultimately improve the quality of life for persons with epilepsy.

This learning guide is developed within an ECTS (European Credit Transfer System) framework, to ensure translatability within Europe for life- long learning purposes.

Glossary of Key Terms and Concepts

https://ec.europa.eu/epale/en/newsletters/how-improve-adult-learning-people-disabilities

Term	Definition	Reference
Assessment methods	The whole range of written, oral and practical tests/examinations, projects, performances, presentations and portfolios that are used to evaluate the learner's progress and ascertain the achievement of the learning outcomes of an educational component (unit/module).	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Assessment criteria	Descriptions of what the learner is expected to do and at what level, in order to demonstrate the achievement of a learning outcome. The assessment methods and criteria for an educational component have to be appropriate and consistent with the learning outcomes that have been defined for it and with the learning activities that have taken place.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Award of credits	The act of formally granting students and other learners the credits that are assigned to the qualification and/or its components if they achieve the defined learning outcomes. National authorities should indicate which institutions have the right to award ECTS credits. Credits are awarded to individual students after they have completed the required learning activities and achieved the defined learning outcomes, as evidenced by appropriate assessment. If students and other learners have achieved learning outcomes in other formal, non-formal, or informal learning contexts or timeframes, credits may be awarded through assessment and recognition of these learning outcomes.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Bologna Process	In 1999 the Bologna Declaration included ECTS among the main objectives to be achieved by countries participating in the Bologna Process. Through the reforms implemented in the course of the Process, ECTS has become a key tool of the European Higher	European Commission (2005). Framework for Qualifications for the European Higher Education Area; Bologna Working Group on Qualifications Frameworks, published by the Ministry of Science, Technology and

	Education Area (EHEA), the establishment of the European Higher Education area, the consolidation of lifelong learning, the paradigm shift from teacher-centred to student-centred higher education, the increasing use of learning outcomes, and the development of new modes of learning and teaching. It includes a specific focus on programme design and delivery, and builds on the experience of higher education institutions in using qualifications frameworks and in applying ECTS principles in academic practice.	Innovation, Copenhagen, February 2005. http://www.ond.vlaanderen.be/hogeronderwijs/bologna/documents/050218_QF_EHEA.pdf
Competence	The European Qualifications Framework (EQF) defines competence as the ability to use knowledge, skills and personal, social and/or methodological abilities, in work or study situations and in professional and personal development. In the context of the EQF competence is described in terms of responsibility and autonomy. Fostering competences is the object of all educational programmes. Competences are developed in all course units and assessed at different stages of a programme. Some competences are subject-area related (specific to a field of study), others are generic (common to any degree course). It is normally the case that competence development proceeds in an integrated and cyclical manner throughout a programme	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Continuing Professional Development (CPD)	An aspect of lifelong learning, sometimes referred to as Continuing Professional Education, CPD describes the skills, knowledge and experience that an individual gains formally and informally in his work and which builds on his basic qualifications and training. Increasingly in professional and vocational careers there is a formal requirement to continue to learn and develop knowledge, skills and competences throughout careers to keep up to date and be able to work safely, legally and effectively. Formal CPD which is a professional requirement is validated and documented. Increasingly employers expect to have a formal authenticated record of an individual's CPD and it consequently has become an important element in the curriculum.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Course Catalogue	The Course Catalogue includes detailed, user-friendly and up-to-date information on the institution's learning environment (general information on the institution, its resources and services, as well as academic information on its programmes and individual educational components) that should be available to students	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning

	before entering and throughout their studies to enable them to make the right choices and use their time most efficiently. The Course Catalogue should be published on the institution's website, indicating the course/subject titles in the national language (or regional language, if relevant) and in English, so that all interested parties can easily access it. The institution is free to decide the format of the Catalogue, as well as the sequencing of the information. It should be published sufficiently in advance for prospective students to make their choices.	
Course unit	A self-contained, formally structured learning experience. It should have a coherent and explicit set of learning outcomes, defined learning activities consistent with the time allocated within the curriculum, and appropriate assessment criteria.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Dublin Descriptors	The Dublin Descriptors are the cycle descriptors (or 'level descriptors') presented in 2003 and adopted in 2005 as the Qualifications Framework of the European Higher Education Area. They offer generic statements of typical expectations of achievements and abilities associated with awards that represent the end of each of a (Bologna) cycle or level. The descriptors are phrased in terms of competence levels, not learning outcomes, and they enable to distinguish in a broad and general manner between the different cycles. A level descriptor includes the following five components: • knowledge and understanding • applying knowledge and understanding • making judgements • communication • lifelong learning skills	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Educational component	A self-contained and formally structured learning experience (such as: course unit, module, work placement).	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
ECTS credit	European Credit Transfer and Accumulation System. A learner-centred system for credit accumulation and transfer, based on the principle of transparency of learning, teaching and assessment processes. Its objective is to facilitate planning, delivery and evaluation of study programmes and student mobility by	European Higher Education Area (EHEA) (2008). Bologna Framework and Certification. www.ehea.info/Uploads/QF/Bologna_Framework_and_Certification_revised_29_02_08.pdf Bologna Conference (2004). Using Learning Outcomes,

	recognising learning achievements and qualifications and periods of learning. ECTS European Credit Transfer System credits express the volume of learning based on the defined learning outcomes and their associated workload. One ECTS credit is approximately equivalent to 25-30 hours of student work, 5-7 hours of which consist of direct lecture time in the case of taught ECTSs.[1]	Edinburgh, 1-2 July 2004. http://www.ehea.info/article-details.aspx?ArticleId=119
European Qualifications Framework for Lifelong Learning (EQF)	The European Qualifications Framework for Lifelong Learning is a common European reference framework which enables countries of the European Union to link their qualifications systems to one another. It was adopted by the European Parliament and Council on 23 April 2008. The EQF uses eight reference levels based on learning outcomes that are defined in terms of knowledge, skills and competence. It shifts the focus from input (lengths of a learning experience, type of institution) to what a person holding a particular qualification actually knows and is able to do. It makes qualifications more readable and understandable across different countries and systems in the European Union.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Informal learning	Learning resulting from daily activities related to work, family or leisure which is not organised or structured in terms of objectives, time or learning support; it may be unintentional from the learner's perspective; examples of learning outcomes acquired through informal learning are: skills acquired through life and work experiences, project management skills, ICT skills acquired at work, languages learned, intercultural skills acquired during a stay in another country, ICT skills acquired outside work, skills acquired through volunteering, cultural activities, sports, youth work and through activities at home e.g. taking care of a child (Council Recommendation 2012/C 398/01).	
Learner	An individual engaged in a learning process (formal, non-formal or informal learning). Students are learners involved in a formal learning process.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Learning outcome	Statements of what a learner knows, understands and is able to do on completion of a learning process. The achievement of learning outcomes has to be assessed through procedures based on clear	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning

[1] In UK, 2 UK credits = 1ECTS credit. Higher education credit framework for England: guidance on academic credit arrangements in higher education in England August 2008 http://www.universitiesuk.ac.uk/highereducation/Documents/2008/CIDG_HE.pdf p8

	and transparent criteria. Learning outcomes are attributed to individual educational components and to programmes at a whole. They are also used in European and national qualifications frameworks to describe the level of the individual qualification.	
Learning Outcomes	Learning outcomes are statements of what the individual knows, understands and is able to do on completion of a learning process. The achievement of learning outcomes has to be assessed through procedures based on clear and transparent criteria. Learning outcomes are attributed to individual educational components and to programmes at a whole. They are also used in European and national qualifications frameworks to describe the level of the individual qualification.	European Commission (2015). ECTS Users' Guide. Luxembourg. Publications Office of the European Union, 2015. http://ec.europa.eu/education/library/pubications/2015/ects-users-guide_en.pdf p 20
Learning pathway	Learning pathway is a route taken by a learner allowing him/her to build knowledge progressively and acquire the desired set of competences. The learning pathway may be 'signposted' through institution guidance and regulations (including the recognition of prior learning and experience) and different learning pathways may lead to the award of the same qualification. In essence the concept of a 'learning pathway' emphasises the choice of the student in reaching the desired educational goals	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Lifelong learning	All learning activity undertaken throughout life, with the aim of improving knowledge, skills and competences within a personal, civic, social and/or employment-related perspective (Communication (2001) 678). Programmes and services contributing to lifelong learning within the higher education sector may include mainstream programmes, continuing education, evening classes, specific programmes for part-time learners, access to libraries/higher education institution resources, distance learning, training courses, targeted guidance and counselling services among other actions and initiatives.	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Non-formal learning	Learning which takes place through planned activities (in terms of learning objectives, learning time) where some form of learning support is present (e.g. learner-teacher relationships); it may cover programmes to impart work skills, adult literacy and basic education for early school leavers; very common cases of non-formal learning include in-company training, through which companies update and improve the skills of their workers such as ICT skills, structured on-line learning (e.g. by making use of open	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning

	educational resources), and courses organised by civil society organisations for their members, their target group or the general public (Ibid.).	
Open Educational Resources (OER)	Digitised materials offered freely and openly for educators, students and self- learners to use and reuse for teaching, learning and research; it includes learning content, software tools to develop, use and distribute content, and implementation resources such as open licenses; OER also refers to accumulated digital assets that can be adjusted and which provide benefits without restricting the possibilities for others to enjoy them (Ibid.).	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Student-Centred Learning	A learning approach characterised by innovative methods of teaching which aim to promote learning in communication with teachers and students and which takes students seriously as active participants in their own learning, fostering transferable skills such as problem-solving, critical and reflective thinking (ESU, 2010).	http://ec.europa.eu/education/ects/users-guide/glossary_en.htm#lifelong-learning
Study Program	This is a series of accreditated courses or modules leading to an academic award, such as diploma, Bachelor, Masters, PhD.	European Commission (2015). ECTS Users' Guide. Luxembourg. Publications Office of the European Union, 2015. http://ec.europa.eu/education/library/pubications/2015/ects-users-guide_en.pdf, p 28
Workload	Workload is an estimation of the time the individual typically needs to complete all learning activities such as lectures, seminars, projects, practical work, work placements and individual study required to achieve the defined learning outcomes in formal learning environments. The correspondence of the full-time workload of an academic year to 60 credits is often formalised by national legal provisions. In most cases, workload ranges from 1,500 to 1,800 hours for an academic year, which means that one credit corresponds to 25 to 30 hours of work. It should be recognised that this represents the typical workload and that for individual students the actual time to achieve the learning outcomes will vary.	European Commission (2015). ECTS Users' Guide. Luxembourg. Publications Office of the European Union, 2015. http://ec.europa.eu/education/library/pubications/2015/ects-users-guide_en.pdf, p 77

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Programme of Study: EPIPICTO

Section A – General Information

A1	**Study-unit Code**	EPI-1000
A2	**Study-unit Title**	EPIPICTO: a pictoral guide for adults with epilepsy
A3	**Level**	Life Long learning
A4	**ECTS Credits**	1 ECTS
A5	**Study-unit Type**	Elective
A6	**Period of Study**	Year
A7	**Entity Offering ECTS**	Relevant IBE affiliate Epilepsy Organisation
A8	**Estimated Student Numbers**	10
A9	**Maximum class size**	One to one sessions preferred
A10	**Mode of Attendance**	PT after hours (Taught)

Section B – Rationale for study unit

<table>
<tr><td>B1</td><td colspan="2">Rationale for new unit</td></tr>
<tr><td></td><td colspan="2">Epilepsy is one of the most common chronic neurological disorders affecting around 1% of the population worldwide.. This study units aims to address adults with epilepsy who are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe and persons with low literacy levels and low health literacy.

There are adults with epilepsy who are at the risk of increased social exclusion.
• migrant persons,
• persons living in isolated areas in Europe
• persons with low literacy levels and low health literacy.

These persons are marginalised not only because of their health conditions, but also stigma and discrimination.

This guide will give an overview of some ways in view we can facilitate self-management in epilepsy, both on a national as well as on an EU level</td></tr>
<tr><td>B3</td><td colspan="2">From which academic year will this unit become available/change?</td></tr>
<tr><td></td><td colspan="2">2019-2020</td></tr>
<tr><td>B5</td><td colspan="2">By which entity has this study-unit been approved?</td></tr>
<tr><td></td><td>Entity:</td><td>EPIPICTO consortium</td></tr>
<tr><td></td><td>Minuted Decision & Date:</td><td>July 2019</td></tr>
</table>

Section C - Study-unit details

C1	**Name and status of Coordinating Lecturer**	IBE affiliated trainer
	Co-lecturer/s (if any) and status	IBE affiliated trainer
C2	**Pre-Requisite qualifications**	none
C3	**Description of this Study-unit**	
	EPIPICTO is a pictorial guide to epilepsy for people who have limited literacy skills or who are new arrivals in Europe with limited understanding of the local language. This guide aims to address adults with epilepsy who are at the risk of social exclusion such as migrant persons, persons living in isolated areas in Europe and persons with low literacy levels and low health literacy. These persons are marginalised because of their health conditions, stigma and discrimination. The contents will explain • what epilepsy is and what it is not (dispelling myths), • medication and treatment options, • epilepsy first aid, • how to reduce seizure frequency • information for families. Graphics will be used extensively for the guide, to create appropriate images complementing the minimal text used.	
C4	**Study-unit Aims**	
	The project will contribute to the social inclusion of these persons by using a pictorial guide to overcome language barriers and literacy issues. This will improve their access to social, health, education and employment services and help them to better manage their epilepsy. It will result in a better quality of life for these persons. The project brings together five European epilepsy organisations from Austria, Germany, Malta, the Netherlands and Scotland. The aim of this curriculum and learning guide is to facilitate the use of the EPIPICTO pictorial guide among trainers. The guide should complement one to one sessions with e**xamples of learning activities such as :** - Identifing coping strategies in their lifestyle - Learning how to express themselves in a group - Seeking information about patient organizations - Listing main causes of seizures - Listing triggering factors and ask patients whether they have observed by themselves triggering factors - Learning how to use an epilepsy diary	

C5

Learning Outcomes

1. Knowledge and Understanding: By the end of the study unit the student will be able to:

- learn that epilepsy is common and can happen to anyone, at any life stage, and of any ability, and that the person with epilepsy is not to blame.
- be aware of personal feelings that are associated with a (chronic) condition such as epilepsy
- express his/her feelings in relation to the condition
- understand the importance of seeking medical advice and adhering to treatment plans.
- if the person is a woman of childbearing potential, learn the importance of seeking medical advice before becoming pregnant
- learn how to live with epilepsy (what the patient can do if negative feelings surmount him/her)
- to learn how to communicate about the condition within the families
- be aware of the difficult adjustment of families to the family member with a chronic condition

2. Skills (including transferable/generic skills): By the end of the course the student will be able to:

- recognise different types of seizure
- recognise different types of triggering factors
- be able to explain to colleagues and family about how seizures should be managed,
- learn how to record seizures,
- apply first aid in epileptic seizures,
- make healthy lifestyle choices in relation to diet, exercise, sleep and alcohol consumption
- make life choices with respect to choice of work
- apply driving rules
- take a balanced approach when understanding risk and safety in living with epilepsy.

C6

Teaching and Learning Methods

Method	**Number of Sessions**	**Duration hours each**
Independent Study	4	2
Independent online learning	4	2
Group learning	2	2
Other (please specify)- one to one learning	3	2
Total learning hours *(FOR 1 ECTS credit: should amount to 25-30 hours, of which 5-7 hours are direct lecture time)*		26 hours

C7	Method of assessment	Duration in hours or length in words (as applicable)	Percentage weighting
	Task		
	Other (please specify)		

C8 Main Text/s and any supplementary readings

EPIPICTO website www.epipicto.eu
Caritas Malta Epilepsy Association www.caritasmalta.org/services/epilepsy
Epilepsie Dachverband Österreich (EDO) www.epilepsie.at
Epilepsy Connections (Scotland) www.epilepsyconnections.org.uk
Interessenvereinigung für Anfallskranke in Köln e.V. www.epilepsie-selbsthilfe.de/koeln
Stichting Epilepsie Instellingen Nederland (SEIN) www.sein.nl
IBE website www.ibe-epilepsy.org
Epilepsy Action UK www.epilepsy.org.mt
Epilepsy Society UK www.epilepsysociety.org.mt
Epilepsy Foundation www.epilepsy.com

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